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Dual Diagnosis of mental illness and acquired brain injury: Making positive changes towards rehabilitation and recovery

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**ABSTRACT**

Aim: The aim of this exploratory study was to describe some of the challenges faced by people with dual diagnosis of Acquired Brain Injury (ABI) and Mental Illness (MI); and from these findings make recommendations on service practices and policies required for an effective post discharge rehabilitation and recovery pathway. Methods: This study used in-depth interviews of eight individuals and/or their families, and case managers. Qualitative analysis was used to identify key themes. Findings: Participants faced a lack of appropriate supports which reflected a deficiency of expertise in understanding the complex needs of people with ABI and mental illness. Participants were categorized as having ABI or MI leading to lack of engagement in meaningful activities, suitable employment opportunities and a lack of appropriate supports for families.

**Keywords:** Brain Injury, Recovery Treatments, Service Provision

**Introduction**

The aim of this exploratory study was to describe some of the challenges faced by people with the dual diagnosis of acquired brain injury (ABI) and mental illness (MI). The study explored the lived experiences of people with ABI/MI and their families/carers to identify barriers and enablers to their rehabilitation and recovery. The results of this study will contribute the development of policy and practice and provide a basis for future research into the complex needs of this group.

**Background**

An acquired brain injury is any damage caused to the brain after birth. The statistics on the incidence of ABIs worldwide are uncertain (Headway, 2012), however the Australian Institute of Health and Welfare (2007) reported that there were 432,700 people with ABI in Australia. The most common causes of ABI in Australia are stroke and accident or trauma (Brain Injury Australia, 2012). Acquired brain injury is a “complex and individualized condition”, that affects not only the person’s physical functioning but their cognitive and emotional functioning as well (Headway, 2012; Brain Injury Australia, 2012). When combined with a mental illness, the person’s rehabilitation and recovery is significantly affected.
Research on the dual diagnosis of ABI and mental illness is limited. Mental illness can occur prior to and following the onset of ABI. There is a significant association between mental illness and acquired brain injury, with depression occurring often enough for it to be considered a common consequence of ABI (Rosental, Christensen & Ross, 1999; Fann et al., 2002). Max et al., (1998) identified family dysfunction and family psychiatric history as a risk factor for the onset of mental illness in children and adolescents with a brain injury. Within Western Australia it is believed 42% of people living with ABI have a mental illness (Fortune & Wen, 2009).

A common theme in current literature is relationship breakdowns and social isolation. Jones et al., (2010) identified that people with ABI experience changes in social relationships and relationships breakdowns due to loss of sensitivity and ability to express empathy. Johnston, Goverover & Dijkers (2005) found that involvement in social activities for people with ABI is viewed as being less important than involvement in other activities. McGlynn (2005) recommended that clinicians should involve family and social networks in order to support relationships and manage social isolation.

Of the people with ABI in Australia, 157,500 report severe limitation in their ability to engage in activities (Australian Institute of Health and Welfare, 2007). Torsney (2004) found that people with ABI need to be given options throughout the rehabilitation process which should include choices around involvement in meaningful activities, including employment. The employment of people with ABI/MI is a particular problem. A study by Johnston, Goverover & Dijkers (2005) found that twelve months following onset of ABI, only 22.8% of participants were in full time employment. The lack of employment opportunities for people with ABI has been linked to poor community reintegration outcomes and the development of a depressive illness (Ownsworth et al., 2011). There is a lack of research evaluating interventions to assist people with ABI/MI to reintegrate into the community, obtain employment and receive the supports that are required during this transition.

Mental Health clinicians would benefit from training in methods to assist people with ABI/MI to reintegrate into the community. Brain Injury Australia (2007) found that many mental health clinicians were “unaware that a significant percentage of their clients may have an ABI” p. 7. Similarly, Torsney (2004) found that clinicians working in mental health services overlook the importance of the ABI and focus on the client’s mental health which is complicated by a lack of reporting of ABI incidents by families to the mental health clinician. The report completed by Brain Injury Australia (2007) also found that people with ABI/MI “are often refused access and treatment by mental health services throughout Australia” as they do not fit the criteria for services p. 7. The changeable and sometimes challenging behaviours, emotionality and limited insight of a person with ABI/MI also makes traditional mental health group therapy treatments an overwhelming experience (Tornsey, 2004). This emphasizes the need for specific services to meet the needs of people with ABI/MI.

As discussed the needs of a person with an ABI/MI are complex. Currently there is little recent data on the prevalence and incidence of ABI/MI, as well as a lack of understanding around core issues in their pathway to recovery. Currently in Western Australia, there are currently no services or plans for services specifically for people with ABI/MI. It is with further research into the difficulties experienced by people with ABI/MI that an evidence base to transform current policies and practices can be developed.
Research Method

The proposal for the study was a partnership between Headwest and the Centre for Research into Disability and Society at Curtin University, with funding from the Western Australian Mental Health Commission. All agencies were involved in recruiting participants and reviewing the study’s outcomes. Ethics approval was obtained from the Human Research Ethics Committee at Curtin University.

Eight participants with ABI/MI, five support workers and two family members were interviewed. Seven men and one woman aged between late teens to fifty were interviewed. The participants were living in care facilities, mental health services or in their own homes.

Informed consent was obtained from all participants. 19 interviews took place with some participants interviewed twice. All interviews were completed at a venue appropriate for the participant and went for at least half an hour. Interviews were audiotaped and transcribed. Transcriptions were reviewed by three or four researchers for key themes. The researchers met to cluster the key themes into broader themes.

Results

Key themes were identified which included loss, personal development, occupation, family and service provision. All participants had an experience of loss, including the loss of relationships and social roles. Family members experienced loss of personal pursuits due to having to take on a carer role. Participants with ABI/MI reported a loss of independence and the loss of opportunities to make their own decisions. Participants with ABI/MI described experiencing loneliness and difficulties expressing their emotions effectively which lead to loss of relationships and social roles. One participant reported “Well, I felt quite alone…. It was good to see that there were other people like me having the same problems as me”. Occupation was another common theme with participants experiencing a lack of meaningful occupation “doing nothing” or hanging around”. Being involved in occupational activities depended on what services were able to provide to the participant and were not necessarily suitable. The involvement of family was another important theme that was identified. Families reported a lack of support on how to manage the challenging behaviours of the person with ABI/MI. Participants with ABI/MI placed high value on the support and assistance they received from their families, and this was important in their recovery.

Service response was particularly influential on the recovery of the participant with ABI/MI. Participants identified the need for assistance from services with returning to work, developing independent living skills and providing support and advocacy when communicating with health professionals. Participants felt that service providers had little understanding on ways to effectively work with people with ABI/MI. The provision of suitable accommodation was an issue with a lack of choice around where they lived “they’re forced into this situation, when they’re strangers they have to live with”. As referred to above, families reported a lack of support and the need for services to assist with developing the families skills in managing the challenging behaviours of the person with ABI/MI.
Discussion

From the findings of this study it is recommended that an efficient plan is developed for the rehabilitation of people with ABI/MI and their families. Emphasis should be placed on providing services to assist people with ABI/MI to participate in meaningful occupations which include employment. The need for support services for their families is also evident. Further research in this area is also needed to improve the understanding of the complex needs of people with ABI/MI.

Acknowledgements

We would like to acknowledge the participants with ABI/MI and their families for their involvement in the study. We would also like to thank the service providers for their positive and honest perceptions on their experiences.

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Supporting young Australians to increase help seeking behavior and improve wellbeing: a preventative and early intervention approach developed across Australian Red Cross Youth Programs

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**ABSTRACT:**

One in four young people will experience a mental health problem in any given 12 month period. If they receive support and help early, they are less likely to experience a recurrence of mental health problems in the future. Australian Red Cross is responding to these facts by working with young people in a peer-centered, early intervention framework across all our youth mental health initiatives and services.

This presentation will examine the need for culturally appropriate, youth centred, peer education support programs, and the challenges and strengths in designing peer-led programs with a community development focus.

**Keywords:** Early interventions, Prevention treatments
Australian Red Cross is committed to promoting positive mental health and wellbeing for young people. Working in partnership with beyondblue, the national depression and anxiety initiative and FACHSIA, Australian Red Cross have developed three different youth centred peer education programs that address issues arising from poor mental health and wellbeing. Adolescence is one of the most rapid developmental periods during our lifespan and as a result of the many changes that occur during this time young people can often become vulnerable to mental health difficulties. In some instances, it can be difficult to distinguish normal adolescent experience from emerging mental health problems. During the early teens to the mid-20s, young people are most likely to experience the emergence of ill mental health, with 1 in 4 living with ill mental health in any 12 month period. Moreover, 75% of mental illness occurs before the age of 25.

Despite these statistics, research indicates that only 30% of young people who would benefit from professional help actually access mental health services. Mental illness experienced during adolescence is often associated with impaired social functioning, poor educational achievement, unemployment and substance abuse, which may also lead to a cycle of poverty and disadvantage. Research indicates, however, that if young people receive support and access help early; they are less likely to experience a recurrence of mental health problems in the future, thus moving towards breaking the cycle of poverty and disadvantage. Red Cross is responding to this by delivering early intervention and preventative programs that are relevant and engaging for young people.

Talk OUT Loud is a strengths-based, solution-focussed, peer education program that delivers targeted mental health information and skills development to young people aged 14-25 years. Developed in conjunction with Orygen Youth Health, the psycho-educational program increases mental health literacy, reduces stigma surrounding mental health problems, and strengthens self-care and help-seeking skills amongst young people. Talk OUT Loud is designed to build individual resilience and strong peer support networks for young people. It is delivered by young educators who are trained to provide supportive responses to their peers in response to mental health vulnerabilities.

In addition, Talk OUT Loud is designed to increase a community’s understanding of the impact of poor mental health on a young person’s life; thus reducing stigma and discrimination and developing the capacity of the community to respond to the needs of its young people. Talk OUT Loud is particularly effective in rural and regional communities of Australia. Red Cross has successfully implemented the program in rural NSW, Victoria, Queensland and South Australia.

During 2010-11, Red Cross delivered Talk OUT Loud workshops to over 1800 young people. An evaluation of the Talk OUT Loud pilot undertaken in 2007 by the Hunter Institute for

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5 beyondblue. http://www.beyondblue.org.au
Mental Health, found that participants in Talk OUT Loud training showed increased knowledge about mental health and mental illness, and were ‘significantly more likely’ to engage their peers in conversations about these issues. Participant’s also demonstrated reduced stigma associated with ill mental health after the training.

Red Cross is also committed to working with Aboriginal communities to address the social and emotional wellbeing of Aboriginal young people, who continue to face severe and complex disadvantage. Research consistently reinforces the dire health situation of Aboriginal and Torres Strait Islander peoples, and particularly of young people: 6

- In 2008, 7 out of 10 Aboriginal children were living in families that had experienced three or more major life stress events in the past year (e.g. death in the family, serious illness, family breakdown, financial problems, arrest). These children are more likely to be at high risk of clinically significant emotional or behavioural difficulties.

- Aboriginal and Torres Strait Islander peoples are twice as likely to report high or very high levels of psychological distress as other Australians, and twice as likely to be hospitalised for intentional self-harm.

- The death rate for ‘mental and behavioural disorders due to psychoactive substance use’ was 14 times higher for Indigenous males and 12 times higher for Indigenous females aged 35-44 years than for their non-Indigenous counterparts.

- Indigenous people are more likely to die from intentional self-harm and assault than other Australians. For Indigenous males living in Queensland, WA, South Australia and the NT in 2001-2005, the leading cause of death from injury was suicide.

- Past policies and practices of forced separation of Aboriginal people from their natural families have significantly impacted on the ability of Aboriginal carers to nurture the social and emotional wellbeing of their children. Children of Indigenous carers who had been forcibly separated from their families were more than twice as likely to be at high risk of incurring clinically significant emotional and behavioural difficulties, and had twice the rates of alcohol and other drug use.

- Substance misuse (including alcohol, illicit drugs and petrol sniffing) is a major cause of health problems for Aboriginal peoples.

It was crucial to recognise that the only way to respond to the above needs effectively was to adopt an approach that addressed social and emotional wellbeing issues within the cultural frameworks of Aboriginal communities. Red Cross and beyondblue, worked in partnership to develop SAM Our Way, a national program addressing social and emotional wellbeing needs of young people aged 16-26 in remote Aboriginal communities. These young people typically face a myriad of challenges and issues, including depression, anxiety, violence, risky sexual behaviours and alcohol, drug and other substance misuse.

SAM Our Way is a run within a community development framework, enabling a range of community-specific and culturally relevant projects to be undertaken. Within this framework,

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the SAM Our Way worker in each community works alongside young people, families and local organisations to identify key health and wellbeing issues of concern to them and to build the resilience and capacity of young people to address these issues for themselves.

SAM Our Way is currently operating in 14 program sites, located in regional and remote Indigenous communities in Queensland, South Australia, Western Australian and the Northern Territory. Aboriginal communities are diverse and SAM Our Way responds to local needs, encompassing mental, physical, cultural and spiritual health. The common element of all SAM Our Way projects is a suite of health promotion and training programs – principally save-a-mate (SAM)\(^7\) and Talk Out Loud \(^8\) – which equip young people with skills and knowledge around alcohol and other drug use and mental health, building their capacity to support themselves and their peers who may be experiencing issues. These health education programs are always tailored to the specific needs of each community. The national impact of SAM Our Way is also significant. As Aboriginal communities are empowered to identify and respond effectively to the social and emotional wellbeing issues of their young people, the flow-on impacts will be wide-ranging and are likely to include: reductions in incarceration and recidivism rates; reductions in alcohol and other drug misuse; reductions in suicide and self-harm; decrease in preventable disease, improved psychosocial health and wellbeing; and stronger, more empowered communities.

Young people who have participated in SAM Our Way have reported a range of positive impacts, including:

- Learning how to manage their health and wellbeing, and developing better coping strategies to deal with stressful events
- Becoming more confident and gaining self-esteem through developing new skills and participating actively in their communities
- Connecting with support services and training and development opportunities in their communities

\(^7\) Australian Red Cross has been delivering SAM since 1997 to a range of groups across Australia, including injecting drug users, sex workers, prisoners, at risk and Aboriginal youth. In 2008 our SAM program received a major international award for 'Innovative Drug Policy' at the United Nation’s Commission on Narcotic Drugs meeting in Vienna. It was particularly commended as 'an important initiative in drug policy and a powerful illustration of how a health-based approach to drug policy effectively and poignantly relieves suffering and reduces drug-related damage to individuals, families and society.' SAM is now being delivered by Red Cross Societies in New Zealand, Botswana, France, Spain, Britain, Ireland and Estonia.

\(^8\) Talk Out Loud, developed by Red Cross in partnership with beyondblue and Orygen Youth Health. It was evaluated in 2007 by the Hunter Institute for Mental Health with funding from beyondblue. The evaluation found that Talk Out Loud was successful in achieving its aims – including increasing mental health literacy amongst young people, reducing stigma and promoting help-seeking behaviours.
In many remote areas Red Cross delivers the PHaMS program in conjunction with SAM Our Way to deliver a more targeted approach to poor social and emotional wellbeing. Working in partnership with FACHSIA, Red Cross has implemented the PHaMs program to assist people on their journey of recovery from mental illness. Working from a model that focuses on case workers but incorporates peer workers in two sites, the program supports people in developing skills, building confidence, accessing services and participating in their community. The program focuses on strengths and emphasises that recovery from mental illness is a personal journey that is driven by the participant, builds on the participants strengths and is guided by the participants goals.

PHaMS, SAM Our Way and Talk OUT Loud are delivered within a health promotion framework that utilises peer education and peer leadership models. This ensures that the leadership skills of locally based young people are nurtured and developed so that the program can continue to be implemented after Red Cross’ involvement. An overarching aim of both programs is to work with local communities to identify young people who will take a leadership role within the programs and champion positive messages around resilience, mental wellbeing and supporting your peers. This element of these Red Cross programs ensures that SAM Our Way, PHaMs and Talk Out Loud outcomes are sustainable and have the maximum impact.
Title for Paper

Understanding complex trauma and a Trauma-informed Approach to Care

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ABSTRACT

The majority of people presenting to mental health services have experienced complex trauma (secondary to child abuse, neglect or family violence/dysfunction). This presentation highlights the importance of always considering the possibility of undisclosed or unaddressed childhood trauma underlying mental health presentations.

It challenges the medical model in categorising complex trauma and explores value in asking the question: “What happened to you?” at the core of many consumers’ presentations. Without addressing the core issues of their trauma these consumers will continue to ricochet around the system and have poor outcomes.

This presentation will highlight the need for a public health approach which incorporates both a trauma-informed to care and trauma specific services.

Keywords:
Recovery treatment
Complex trauma
Trauma-informed care

Understanding complex trauma and a Trauma-informed Approach to Care

Trauma seriously impacts mental and physical health, well-being and behaviour. It affects not only those who experience it but those with whom they have contact and the children they may go on to have. Individuals' and society’s responses to trauma vary enormously but the majority of people who present to services with trauma-related problems have multiple unresolved traumas (complex trauma) which often leads to severe, diverse and persistent impacts.

Complex trauma can be caused by childhood abuse in all its forms as well as neglect and growing up with family violence or dysfunction. Any form of violence experienced within the
community – civil unrest, war trauma, genocide, cultural dislocation, sexual exploitation or re-traumatisation of victims later in life can also cause complex trauma.

In complex trauma the traumatic stressors are usually *interpersonal* – the trauma is premeditated, planned, and often repeated and prolonged and the impacts are cumulative. While interpersonal trauma can be one off events such as a physical or sexual assault, perpetrated by a stranger child abuse is more commonly perpetrated by adults on whom the child depends and trusts – family members or other adults in regular contact through school, church, sports or other community activities.

It’s important to differentiate single incident trauma often classified in terms of PTSD from complex trauma and deliver service responses accordingly as responses to complex trauma based on a diagnosis of PTSD alone are often seriously inadequate.

With child abuse the trauma is developmental. Research establishes the profound effects of extreme experiences not only on the developing brain in infancy but *throughout the life cycle*. It has provided the scientific basis for a diversity of behaviours and reactions to trauma, previously only observed.

Furthermore new research shows that with appropriate working through the trauma of even severe early experiences can be resolved. It suggests that changes to the brain occur in both directions – just as damaging experiences cause changes in the brain that are negative for subsequent functioning, new, different and positive experiences also change the brain in ways that are conducive to health. The challenge is to translate this research into effective practice.

Trauma is associated with an array of so called co-morbid problems including mental health challenges, poor physical health, substance abuse, eating disorders, relationship and self-esteem issues and contact with the criminal justice system. However I’d like to suggest that they are not co-morbid at all but rather an individual’s multitudinous responses to the lived experiences of trauma.

By way of illustration I would like to share a bit of my personal story. I am a survivor of child sexual and emotional abuse, the impact of which I have grappled with for over a decade. My story of recovery and beyond has been chronicled in a memoir entitled *Innocence Revisited* – a tale in parts.

As a medical practitioner, one would assume that I was informed about trauma, its effects on mental health and how to address the impact. Nothing was further from the truth! And one might have assumed that my medical colleagues would have been empathic and supportive. When I fell off my perch they bolted faster than anyone. It was as if the contagion of my affliction might strike them down as well!
I was a GP in Sydney for twenty years. I worked hard juggling the demands of practice with being married with 4 children and a foster child. Back then I appeared to do most things with relative ease. In retrospect I was emotionally detached, running on autopilot without the capacity to check in with myself or others.

In April 1998 when I was in my mid 40’s my niece was killed in a car accident. I grieved for her, as one would expect and grieving takes as long as it takes. As other members of my family started to come to terms with their loss I was becoming more distressed. I started to feel anxious and then had my first panic attack. I thought I was going to die! The panic attacks became more frequent, the anxiety generalized and I grew depressed. Then came the nightmares and flashbacks as the trauma stored in my subconscious unlocked.

Soon I could barely function. I reluctantly left work setting myself a 4 month sabbatical - that was 13 years ago. After that my world collapsed. Begrudgingly I consulted a clinical psychologist. Doing so went seriously against the grain as I was fiercely independent and abhorred any signs of weakness especially in myself. It took me an eternity for me to trust her and to feel safe, or understand that she could keep me in mind. Not her fault - all were foreign concepts to me. After some months in therapy it became apparent that I had virtually no memory for 10 years of my childhood. I didn’t appreciate the significance of such a period of traumatic amnesia having always dismissed my poor memory and sticking to my mother’s assertion that I did have a happy childhood. I just couldn’t produce a single fact to support it.

I spent most of the next 2 years in bed, completely immobilized, battling a relentless blackness of mood. I struggled with suicidal thoughts and then gestures. The antidepressants the psychiatrist prescribed helped take the edge off my mood at times, but it was a lengthy psychotherapeutic process which helped me make meaning of my history that finally got me functioning. And needless to say I function in a very different way. I’m more empathic, connected and insightful and have developed a reflective capacity that was previously not on the radar.

Therapy guided my process of integration and I am now well and no longer subsumed in my trauma. I have made sense of my trauma and it is a part of my history rather than all of me. For the first time, I can not only live in the present but embrace a future. Acknowledging and appropriately addressing the repercussions of my complex trauma was core to my recovery. Anything less would have, at worst, seen me lost to suicide, or at best barely functioning in my daily life.
I am one of more than 2 million Australian adults who suffered some form of childhood trauma and I am lucky. I had the resources and the support to make sense of my history and recover. Many don’t.

For over 100 years, clinicians have acknowledged the link between trauma, mental illness and psychosocial disadvantage. However, it was not until the feminist movement in the 1970s which exposed the consequences of interpersonal violence, and the work of clinicians such as Bessel van de Kolk, Babette Rothchild, Judith Herman and others in the 80s & 90s that research findings provided strong evidence about the prevalence and impact of trauma.

A large percentage of those seeking help at a diversity of health and welfare settings have trauma histories. Of patients presenting to mental health services approximately 2/3 have a lived experience of some childhood abuse or neglect, or have grown up with family violence or dysfunction.

Despite the copious research base adult survivors of childhood trauma in Australia have been ignored in mental health policy reform and they have fallen through the cracks in service systems. The reasons for this are various. As a society we are confronted by trauma. Substantial stigma and taboo still exist around abuse, in general, and the legacy of abuse, in particular. There remains a collective denial about the scale of the issue and the often long-term complex needs of many survivors.

There remains a prevailing attitude that, as adults, people should be able to put their abusive childhoods behind them – on their own. Sometimes, the failure to acknowledge the issues extends to those who provide care.

There may be several reasons:

- a mental health system based on a ‘diagnose and treat’ approach to mental health care
- Clinical assessment which focusses on symptoms and signs and not underlying causes;
- A medicalised response for people impacted by trauma which is often not therapeutic;
- differing perspectives on the scientific validation of the lived experience of people presenting with trauma related symptoms;

Physical diseases fit neatly into diagnoses but the repercussions of trauma do not. This is evidence by the fact that many survivors frequently carry an array of diagnoses concurrently and over time. I was once my very own walking DSM IV. Anxiety disorder, depression,
suicidality, Chronic PTSD, Dissociative Disorders. Thankfully my therapist didn't pathologise me.

Given that recognition and integration of experienced trauma is generally considered fundamental to the recovery process this characterization makes little sense. The medical model works on the principle that something is wrong with a person. The substantive core issue of what happened to a person to impact them so profoundly is often relegated to 'interest value' only. With complex trauma something wrong was done to or happened to a person. I developed my mental health challenges because of what had happened to me, so called 'normal' reactions to extremely 'abnormal' circumstances. And as one of my medical colleagues at the time so delicately put it: “You’re not becoming one of those mental health patients are you?” Yet like all survivors I needed empathy, compassion and understanding, not judgement and labelling.

Anyone interacting with survivors needs to understand the effects traumatic life events have on the development of individuals. For me, finding a therapist who validated my experience, who bore witness to what had happened to me, who I learnt to trust, who gave me unconditional support, who listened empathically and who could contain my angst and help me feel and be safe, was crucial to my recovery.

Many adults who have experienced adverse childhood experiences have adopted extreme coping strategies as an attempt to manage overwhelming traumatic stress. These often persist into adult life and many, such as smoking, substance abuse, physical inactivity, overeating and high risk sexual behaviours become risk factors for later health problems.

Other coping strategies include suicidality, self-harming behaviours such as cutting and burning, dissociation, and re-enactments such as abusive relationships. Whilst challenging, in the context of trauma these behaviours make perfect sense.

By way of example let’s talk briefly about the diagnosis of Borderline Personality Disorder. This diagnosis is pathologising. It carries enormous stigma and consumers are often labelled as ‘borderlines’. This depersonalizes them further as they become their condition, this label becoming their identity, a less than human with a fundamentally flawed personality.

The diagnosis implies hopelessness, manipulation and resistance to treatment and consumers internalize these expectations, and they become a self-fulfilling prophecy. No one is denying the challenges of caring for someone who idealises you one minute and denigrates you the next, who makes repeated suicide attempts and is self-harming.

However if the behaviours which characterize BPD are understood in terms of traumatic stress, disrupted attachment, personal invalidation and adaptive coping strategies it is easier to understand and empathise with challenging behaviours and reactions. That person is
communicating the intensity of the pain at their core, as best they can. Over time listening to them and you may be the very first person in their life who has, and listening to their behavior in the context of what happened to them, will help them to trust you and build a relationship which is crucial for their recovery.

Abuse in childhood often sets up lifetime patterns of fear and mistrust. It affects a person’s identity, self esteem and sense of self worth, their relationships not only with themselves but with others and with the world, the ability to regulate emotions, to self-soothe and self-care and to manage stress. Adult survivors often additionally struggle with somatic symptoms and chronic feelings of hopelessness.

When a child is abused the child takes on an inappropriate sense of shame and self-blame and these feelings often continue into adult life. Even though survivors may want to talk about their feelings, their own shame as well as fear of how others will respond can stop them from doing so. Child abuse is about being and feeling unsafe and survivors try to protect themselves from being hurt again. Hence survivors will tend to withdraw, isolate themselves and not seek help and engage in/or sustain treatment.

Survivors can learn how to trust, feel safe, relate to others and manage their emotions and many do go on to live healthy and productive lives but to do so survivors need support, empathy, understanding and respect. Our current systems of care often ignore the underlying trauma at the core of survivors’ issues, not viewing it as pivotal, and often invalidate, negate or dismiss it. Doing so comes at a huge cost, not just to individuals but to families and communities. ASCA witnesses that cost every day in its work.

Every day ASCA receives calls from child abuse survivors who cannot find or afford the care and support they need. They have experienced a health care professional who has been disempowering, re-victimising or otherwise unhelpful; a GP who was uninformed, who didn’t inquire about trauma despite symptoms which were highly suggestive. A worker who didn’t know how to respond to a disclosure, a counsellor, psychologist or psychiatrist they felt had minimized or dismissed their feelings and experiences rather than listening empathically and validating them.

It is staggering how often survivors are told things like “It happened such a long-time ago; there’s no value in talking about it. What does it matter? Stop whingeing about it.” Some workers believe that talking about past traumas is irrelevant and self-pitying or imply that the trauma was the person’s fault, that he/she is carrying on about nothing, making things up, exaggerating, or has a personality disorder.
While some survivors of child abuse show remarkable resilience many are disadvantaged, not only by their trauma but also by the accompanying socio-economic disadvantage. Meeting the needs of adult survivors can be challenging for all of the reasons I’ve outlined (the deep feelings of insecurity, sensitivity of criticism, low self-esteem, difficulties with trust and interpersonal relationships, substance abuse, self-harming, suicidal and risk-taking behaviours with which many survivors struggle).

Recognising the adaptive function of “symptoms” helps reduce guilt and shame, increases self-esteem, and provides a pathway for developing new skills and better adaptations. Validating resilience is important even when past adaptations and ways of coping are causing problems in the present. Survivors need to feel understood and have their experiences heard and validated.

Survivors generally also benefit from making connections between their past experiences and their current situation as part of an integrated recovery journey, making sense of their past, enabling them to ultimately view their abuse as part of their history.

However none of this can occur in isolation. Relationships are crucial to the process of recovery but the nature of those relationships is vital. As the relationships which caused the original trauma were disempowering and controlling, relationships of care and support must be safe, consistent and constructive, non-violent, non-blaming and non-shaming, and feature persuasion and not coercion, ideas and not force, and mutuality rather than authoritarian control.

Establishing firm and clear boundaries as well as predictable environments, and well defined roles allow survivors to feel empowered and re-build a sense of self-efficacy and personal control - factors which are essential to recovering from the overwhelming fear and helplessness that is the legacy of victimisation. Approaches should be collaborative and mutually respectful with the survivor setting the pace. This allows survivors to build on their strengths, and resiliency, and to further develop their coping skills while embracing hope and working towards a positive future.

The high prevalence of complex trauma is frequently unrecognized and subsumed within other diagnoses, where presenting problems are considered in isolation from the unacknowledged underlying trauma. Complex trauma is often compounded when unrecognized. Trauma survivors with complex needs often experience a range of mental and physical health, substance abuse problems and other life burdens. Many trauma survivors
have not connected their current problems and behaviours with their past traumatic experiences and nor have their health workers, a reflection of the prior lack of adequate training around trauma. A holistic approach to care and support is needed and yet to date care is often fragmented with little to no co-ordination between services along with poor referral and follow-up pathways.

Trauma survivors characteristically seek help from a diversity of public, private and community services over a long period of time. Services tend to focus on crisis and risk management which deliver short term rather than the longer-term interventions needed for sustained recovery. In cities and towns it is hard to access expert long term and affordable counselling/therapy and/or skilled groups and workshops. In rural and regional areas services are virtually non-existent. Mainstream services are overstretched and cannot adequately address their needs. There are exceptions; some specialist services are sensitive to survivors’ needs but they are few and far between. Often they depend on an individual rather than a service culture and when the individual leaves, so does the possibility for trauma informed care and sustained recovery.

Services often mirror the power and control experienced in past abusive relationships. Current systems commonly pathologise survivors and their presentations and a lack of awareness around potential triggers leaves survivors open to re-traumatisation. Trauma survivors often experience services as unsafe, disempowering and/or invalidating. Often times they do not know where to turn and effectively give up. Currently the majority of survivors cannot access and/or afford to sustain the holistic support they need to make sense of their histories and work towards recovery.

So what do we need to see? Let’s talk about a trauma informed approach to care.

“Trauma-Informed Care and Practice is a strengths-based framework grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes physical, psychological, and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment.”

TIC is grounded in a thorough understanding of the neurological, biological, psychological and social effects of trauma and violence and the prevalence of these experiences in persons who receive services. Trauma informed care involves the provision of services that do no harm – e.g., that do not re-traumatise or blame victims for their efforts to manage their traumatic reactions.
**Trauma Informed Care & Practice** involves changing assumptions about how we organise and provide services and creates organisational cultures that are personal, holistic, creative, open, and therapeutic. Service providers move from a caretaker to a collaborator role.

A rapidly expanding research base attests to the substantial *public health* costs of unresolved trauma. Recognition, treatment and funding of trauma are a *national priority*. We need to see a public health approach which incorporates both trauma-informed (recognition of trauma in clients and establishment of systems that are aware, responsive and do not exacerbate it) and trauma specific services (specialised capacity to address trauma per se). And an understanding around complex trauma as distinct from single incident trauma and programs and services which meet the needs of those with complex needs as a consequence of a lived experience of compounded trauma.

ASCA has recently completed a set of Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery. These Guidelines distil the last 20 years of national and international research and have established an evidence base around responsiveness to trauma, with pathways to practice and recovery. These Guidelines support the work, in which ASCA is involved, on the Trauma Informed Care and Practice Advisory Working Group, under the leadership of MHCC.

The AWG is seeking to drive a national agenda around trauma informed care and practice. Together these initiatives, once adopted will spearhead the changes needed for mental health policy and practice reform around trauma.

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Supporting Children’s Well-Being in a Year 2/3 Classroom

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ABSTRACT

This paper reports on a project that is enabling a Year 2-3 teacher to better respond to the needs of a class with high numbers of students aged between 7 and 8 years experiencing chronic stress and trauma. Such children are at considerable risk of becoming either chronically hyper-vigilant, whereby they are constantly alert to potential dangers, or dissociative and withdrawn. The project provided resources to support and extend the capacity of the classroom teacher to create a safe environment and individual student’s well-being. These resources include teacher professional development, class activities and routines; opportunities for supported reflection on practice; along with links to relevant professional and service networks for children and families. The impacts of the project are still under evaluation by researchers at the University of South Australia.

Keywords: Early Intervention, school class, student well-being, chronic stress, teacher development
Introduction

Recognizing the importance of the early childhood years to later development, Australian state and federal governments have, over the past decade or so, increasingly focused on providing better support for families with young children at home, in child care and at school. Early childhood is the period of the most rapid brain growth of human beings and neurodevelopmental research over the last decade has emphasised the significance of young children’s daily environment in shaping biological pathways setting life trajectories affecting physical and mental health, learning and behaviour (Mustard 2008). After families, schools provide the environments where children over 5 years spend most of their time. Children’s ability to cope with the social, emotional and behavioural demands of schooling is thus significantly shaped by their experiences in the home and in the early years of school.

To the north of Adelaide in South Australia, Salisbury Communities for Children (SC4C) was established in 2005 with funding from the Australian Government Department of Family and Community Services. It aimed to support families with children aged 0-5 years living in the eastern suburbs of Salisbury. The Socio Economic Index for Areas (SEIFA) scores based on Australian Bureau of Statistics 2006 Census data (AEDI 2010) for these suburbs range from 908 to 937, indicating that these suburbs are more disadvantaged than the average Australian suburb (SEIFA score 1000).

The Australian Early Development Index (AEDI) 2006 results for the Salisbury East area indicated that although about half of the 5-year-olds in that area were performing well in one or more developmental domains, 29 per cent were developmentally vulnerable in one or more domains. To illustrate, as many as 13 per cent were not doing well on measures of emotional maturity; that is they had trouble concentrating, managing their negative emotions and were not ready to help others. AEDI results for 2009-10 also indicated that a larger percentage of children in the eastern Salisbury suburbs than in Australia overall, entered school with difficulties in one or more developmental domains.

In 2009 the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) funded the SC4C to extend its support for children’s development into the primary school years. Following consultations with primary school teachers and children (Diamond & Willoughby 2009), SC4C employed a Children and Families Support Coordinator (CFSC) to work with counsellors, chaplains, Aboriginal liaison and other school staff to create networks between agencies concerned with children and their families, and to provide holistic support in complex cases affecting children aged 5 to 12 years. As part of this initiative a year 2-3 class teacher at a primary school in the eastern Salisbury suburbs volunteered to participate in a project in partnership with the CFSC worker. Its aim was to undertake professional development on young children’s well-being and to implement classroom activities to assist children’s optimal development and resilience. The following section briefly reviews the research literature on children’s exposures to stress and trauma and its impacts on their schooling experience.

Chronic Stress, Trauma, Learning and Resilience

The neuroscience of learning has established that school children who experience chronic stress or traumatization have difficulties learning and integrating new information (Australian Childhood Foundation 2010). Stressors arising from negative family interactions, parental separation, family poverty, neglect, violence, mental illness and substance abuse, neighbourhood violence, racism and discrimination are known to threaten healthy emotional development (Seccombe 2002). Continuing exposure to stressors creates chronic stress responses because the hippocampus, which normally operates to lower cortisol production, becomes damaged allowing high cortisol levels to cause neural injury (Monk & Nelson 2002) and threaten the development of cortical receptors (Gerhardt 2004). Outcomes include memory loss (Abercrombie, Kalin, Thurow, Rosenkranz & Davidson 2003) and depression
The use-dependent brain pathways in chronically stressed children become attuned to detecting and responding to alarm stimuli. Focus on threat and survival means that when these children do not feel safe, effective learning of new information is diminished (Goswami 2008, p.44).

Trauma refers to a response to an overwhelming event where survival is threatened. Common contexts of trauma include war, interpersonal violence, rape and sexual abuse, vehicle crashes, near-death experiences, or witnessing violence, injury, death or disaster (Stien & Kendall 2004). Unfortunately such events are not infrequent. For example one in four Australian children has witnessed violence against their mother (Indermaur 2001).

Childhood trauma impacts on the development and function of the brain, affecting children’s emotional, cognitive, social, physical and behavioural functions. Even a single traumatic experience can alter brain function (Perry 2001). Resultant memory problems including intrusive thoughts, and a state of heightened arousal disrupt the “collaboration between the emotional and cognitive parts of the brain – the limbic system and the neocortex …often lead[ing] children to develop an emotion-based coping style aimed at managing overwhelming feelings rather than thoughtfully tackling the challenges at hand” (van der Kolk 1997 cited in Stien & Kendall 2004, p.75). The need to respond to a perceived threat, when either the situation is traumatic or there are one or more trauma-associated triggers present, has priority over language and thinking and problem-solving areas of brain anatomy that normally regulate emotional expression. Continued exposure to traumatic experiences creates developmental post-traumatic stress disorder where the brain architecture adapts over time to cope with continuing trauma (Streeck-Fischer & van der Kolk 2000). Survival is the goal.

Resultant behaviours include internalising symptoms such as poor concentration, pessimism about the future and stomach aches, or externalising symptoms such as irritability, avoidance of stimuli associated with the trauma, and tantrums (Stien & Kendall 2004). In the classroom context, as well as having an impact on the traumatised child, these behaviours also affect their peers. This means that children who have chronic traumatization find it much more difficult than other children to learn. The hyper-arousal or dissociative states experienced by chronically traumatized children impede access to the brain pathways for cognition, language, reflection and abstraction (Streeck-Fisher & Van der Kolk 2000). Traumatised children may also experience new events or activities as threatening, making it difficult for them to feel safe enough to be open to new information. Traumatized children find it hard to tolerate uncertainty and tend to avoid novel experiences and social contact. This in turn inhibits their exposure to learning new words, social expectations and cultural contexts (Streeck-Fisher & Van der Kolk 2000, p.912) and leaves a consequent gap in their social education.

In the primary school context, children who are identified as vulnerable socially and emotionally are at risk of being rejected by their peers (Laird, Jordan, Dodge, Pettit & Bates 2001). Peer acceptance in the primary-school years is powerfully related to positive psychological adjustment and successful learning. Children who were rejected by peers in primary school are more likely to perform poorly or avoid school; to drop out, become involved in substance abuse and delinquent behaviour in adolescence, and have mental health problems or criminal convictions in adulthood (Laird et al. 2001).

Traumatised and chronically stressed children need to learn how to become successful learners, and to develop new adaptive responses. Assisting children to become aware of their emotional and physical states and to learn strategies to self-regulate when they are feeling stressed or reacting to past traumas provides a pathway to enable improved social and emotional well-being and enable effective learning (Perry n.d ; MacCaskill 2007).
Children who succeed in life despite adversity or stress are considered “resilient” (Naglieri & LeBuffe, 2005). Interpersonal factors associated with resilience are warm, supportive, stimulating, trusting relationships with a competent adult such as a parent, grandparent, mentor, elder or teacher (Masten & Reed 2002), or with siblings or competent peers (Werner 2006). A competent caring adult has been found to provide a healthy model of effective coping, to act as a knowledgeable guide by listening and assisting children to rise to challenges, solve problems, remain persistent, manage stress and succeed despite their life circumstances. Positive interactions with safe and familiar others help to regulate and repair stress response systems and trauma-associated difficulties (Lucy-Dobson & Perry 2010).

High-quality schools, and accessible health care and social services help develop children’s emotional resilience by fostering children’s and families’ physical, social, emotional, and intellectual well-being (Conger & Conger, 2002; O’Dougherty Wright & Masten, 2005; Seccombe, 2002). Masten et al. (2008, p.76) particularly highlight the role of effective schools and teachers, claiming that “a school that functions well in a context of adversity can also be said to manifest resilience”. The World Health Organisation (2010) recommends ‘mental health promotional activities in schools’, and the current Australian National Mental Health Plan (2009) identifies working “with schools…to deliver programs to improve mental health literacy and enhance resilience” as a key action.

The Review of Funding for Schooling in Australia commissioned by the Australian government argued that “Australian schooling needs to lift the performance of students at all levels of achievement, particularly the lowest performers” (Gonski, Boston, Greiner, Lawrence, Scales, & Tannock 2011, p. xxix) It recommended that “school leaders should … make local arrangements to respond to particular needs related to student welfare, mental health and school readiness, and work directly with local public or not-for-profit providers of human services more broadly” (p. 219).

The establishment of an outreach worker in schools to work with staff, children and families by Salisbury Communities for Children has created stronger links between schools and family support services. A partnership between the SC4C outreach worker and a year 2-3 classroom teacher in a local primary school has actively supported children’s well-being. The teacher-led strategy is being evaluated by University of South Australia researchers to determine whether this approach can improve children’s social relationships at school, their ability to identify their own and others’ feelings and their subjective wellbeing, and if so, in what ways. It is expected that student learning will improve if the above outcomes are achieved. The research examines to what extent a classroom teacher led program can improve children’s social and emotional well-being in the school environment.

Research Design and Methodology

Classroom based intervention aimed at supporting children’s well-being has focused on assisting children to recognize their own and other’s feelings and to promote co-operative and safe interactions between students. Five classroom based strategies are currently being implemented during the 2012 school year. These are:

- teacher professional development for the use of “Kimochi” (http://www.kimochis.com.au/) and ‘Play is the Way’ (MacCaskill 2007) resources,
- implementing ‘emotional intelligence’ learning in all aspects of the curriculum,
- using ‘Play is the Way’ (MacCaskill 2007) and Kimochi resources to structure daily classroom activities,
- informing parents about ‘emotional intelligence’ learning and ways they can support this at home, and,
- providing a ‘cool down’ space in the classroom with sensory resources to assist children to self-regulate their emotions.
The strategies and selection of resources were developed by the class teacher, the school’s Child and Family Support Coordinator and the SC4C’s Children and Families Support Coordinator. The University of South Australia researchers are evaluating the project to identify the following five impacts of the project on the children: (a) their social relationships at school, (b) their ability to identify feelings, (c) their ability to manage their own behaviour, (d) their school attendance and (e) their subjective well-being.

Data about the teacher’s professional knowledge and reflections about implementation of classroom strategies are being collected in three one hour interviews conducted at the end of conducted at the end of terms one, three and four. At the end of terms one and four the teacher is asking children to complete a sociogram detailing who they like to play with at school. The teacher is also recording each child’s attendance, achievement and feelings about school, the need to intervene to manage individual children’s behaviour. A parent information evening about the project was conducted in Term 2. The researchers expect that the project can provide useful insights into the efficacy of classroom based intervention to support stressed or traumatized children’s well-being within the school environment.

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A new team for rural mental health promotion - linking sporting clubs and local services

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Abstract

Good Sports, Good Mental Health (GSGMH) has engaged 400 rural community sporting clubs, supporting them to undertake interventions designed to build awareness of depression and anxiety disorders then increase capacity to respond to local mental health issues both from an individual perspective and in the club environment.

Quantitative evaluation involved computer assisted telephone surveys with 311 members drawn from 54 participating clubs. Members were surveyed prior to commencing the program and at completion. The qualitative component of the evaluation involved interviews with key stakeholders.

The evaluation suggested that the program is effective in raising awareness of mental health issues and available support among members of rural sporting clubs and effective in reducing the level of mental health issues in those communities.

Keywords
Launched in 2009, ‘Good Sports, Good Mental Health’ (GSGMH) is a mental health program for community sport clubs. It is delivered by the Australian Drug Foundation (ADF) with funding from beyondblue: the national depression initiative. GSGMH involves supporting community sporting clubs to undertake a number of interventions designed to build awareness of depression and anxiety disorders, then increase both individual and club capacity to respond to mental health issues.

GSGMH interventions include making information about mental health readily available, conducting a club-wide awareness raising activity, demonstrating how to access local services and training for key personnel in the club. More information about these four interventions is provided below. Evaluation was undertaken to determine the effect of GSGMH on local community capacity to identify and respond to mental health challenges.

GSGMH aims to:
1. Raise awareness of mental health issues and available support amongst members of rural sporting clubs to reduce the level of mental health issues in those communities;
2. Utilise community partnership networks already developed through beyondblue’s rural and drought initiatives in the relevant regions; and
3. Assist rural and regional communities to learn to identify local strengths and services (sporting clubs and service systems) and develop the capacity to initiate local partnerships that bring about sustainable change in the understanding and management of depression and anxiety.

GSGMH was established on the strength of the ADF’s Good Sports program which is designed to reduce alcohol related harm in community sporting clubs. Over 5,000 sporting clubs across Australia are registered with Good Sports. Participating clubs progress through an accreditation process, and commit to establishing a club environment that demonstrates responsible use of alcohol. Evaluation of Good Sports suggests that participating clubs have lower levels of alcohol consumption and less drink driving than clubs not participating in the program. Moreover, there is some evidence that as clubs progress through the program they experience an increase in their income, income sources, and female membership (Crundall, 2010). These positive outcomes may be considered a consequence of the change in club environment achieved through addressing the service and role of alcohol in the club.

Good Sports, Good Mental Health is an outcome of the ADF’s engagement with community sporting clubs to address alcohol consumption. The ADF has expanded its work to focus on mental health due to the prevalence of mental illness and the fact that alcohol problems and mental health issues often coexist.

Mental illness is common in Australia with at least 20% of the population experiencing depression at some stage in their life and 25% experiencing anxiety disorders (ABS, 2006; Todd, 2002). It is proposed that at least 30% of people with a mental illness have a co-existing substance use disorder (Todd, 2002). The ADF has piloted GSGMH in regional and rural areas, given that the presence of mental illness in non metropolitan areas tends to be higher than in metropolitan areas. This can be due to greater isolation and stigma presenting barriers to treatment (Pierce, Liaw, Dobell and Anderson, 2010).

Program Method
In Victoria participating clubs were provided with the support of a Project Officer from a regional Sports Assembly or Community Health Centre, while in NSW clubs received the support of an Australian Drug Foundation Community Development Officer. The Project Officers and Community Development Officers helped clubs to complete the interventions, log their achievements with the ADF, and arrange accreditation for clubs that complete GSGMH.

beyondblue and the ADF committed to engage 400 sport clubs throughout rural and regional Victoria and southern NSW in GSGMH between 2009 and 2011. A further partnership has since been undertaken, extending the project into Tasmania.
The interventions that make up *Good Sports, Good Mental Health* were designed on the basis of evidence that suggests that increasing individual ability to connect with others in their community (Pierce et al., 2010) and training programs in the sport setting (Bapat, Jorm and Lawrence, 2009) may contribute to increasing both likelihood of seeking assistance and mental health literacy within communities. As mentioned earlier, in addition to a needs assessment, GSGMH involves four mental health interventions:

- Local service audit
- Information stand
- Mental health awareness training
- ‘Blue’ themed event.

**Local Service Audit**

The purpose of the local service audit is to create a link between clubs and local services that provide mental health support. Either a club representative or their Project Officer creates a poster that provides the contact information of local services in large font. These are displayed in both prominent and discrete locations around participating club rooms. Additionally, contact is made with local services to notify them that the club is working to acknowledge and address mental health issues within their community. Local services are invited to attend the club to present ‘critical facts’ about mental health and to discuss service access pathways. ‘Critical facts’ includes key information on mental health, alcohol and other drugs compiled by beyondblue and the ADF.

**‘bluey’ Information Stand**

*beyondblue* ‘bluey’ information stands are located in club rooms, providing specific flyers and booklets relating to mental health. Clubs are included on the *beyondblue* Australian Rural Information Network and identified as community access points for mental health information. The information stand signifies a commitment to mental health by the club and provides ongoing access to information for members and guests.

**Mental Health Awareness Training (MHAT)**

Two club representatives undertake a 3 hour MHAT course designed to enable participants to identify signs and symptoms of depression and anxiety, and provide initial contact and referral. The training is provided by *beyondblue* and is an adaptation of training developed through the National Drought Campaign, with specific information relevant for sporting clubs. Ideally the members selected to take part in the MHAT are well known in their club and respected leaders, who are then identified as key mental health contacts within the club.

**‘Blue’ Themed Event**

A ‘blue’ event is held within the club to increase club members’ awareness of depression and anxiety and mental health in general and to improve help seeking behaviour (especially among young men). The nature of the event is established through the needs assessment with some clubs undertaking quite simple activities while others undertake community wide events. The ‘blue’ event acts as a launch of the club’s commitment to mental health in a public setting, often receiving local media coverage and in many cases, fundraising for a worthy local cause. The event is also an opportunity to identify the club members who have undertaken mental health training as contact points and to highlight the ongoing presence of an information stand in the club rooms.

The combination of awareness raising and capacity building interventions aims to achieve a lasting and sustainable delivery model which ensures ongoing and long term support to the target audience. GSGMH interventions are designed to raise awareness, and reduce stigma of mental health issues in rural and regional communities through supporting clubs to be welcoming, inclusive and family friendly environments.

**Evaluation Method**

In order to explore the extent to which GSGMH is achieving its aims, the ADF completed an evaluation of the program. The evaluation involves both quantitative and qualitative methods.
In terms of the qualitative aspect of the evaluation, key stakeholders of GSGMH were invited to participate in a semi-structured interview about their experience of the program. Key stakeholders included a beyondblue Manager (n=1) involved in the program, Project Officers & Community Development Officers who delivered the program (n=5), and representatives of clubs that participated in the program (n=4).

Each interview schedule, explored experiences of GSGMH, perceptions of effectiveness, suggestions for improvements and barriers. All interviews were audio-recorded and transcribed.

In terms of the quantitative aspect of the evaluation, telephone surveys were conducted with members of clubs participating in GSGMH prior to program commencement and following program completion. The pre survey was completed between May and December 2010, and the post survey in July 2011. Once club members completed the pre survey their club was able to commence GSGMH.

The aim of this aspect of the evaluation was to gain in depth insight into the extent to which GSGMH achieves its first aim to raise awareness of mental health issues and available support amongst members of rural sporting clubs to reduce the level of mental health issues in those communities.

Telephone surveys explored the extent to which GSGMH led to an increase in club member knowledge of mental health issues; an increase in club member awareness of mental health issues; an increase in club member ability to help someone who may be experiencing mental health issues; an increase in club member capacity to seek help if they experience mental health issues; and a decrease in the stigma club members associated with mental health issues. There was a particular focus on depression and anxiety in each aspect of measurement. This paper explores the extent to which the program was effective in regard to increasing member awareness of mental health issues.

The surveys also asked questions that enabled an assessment to be made of respondents’ mental health, and questions about alcohol consumption. The pre and post surveys were largely identical to allow for direct comparison. Many questions were drawn from beyondblue’s National Depression Monitor on the basis that it covered key areas of interest and also enabled some comparisons to be made with national levels of awareness.

Ethics approval from Deakin University was achieved for this part of the evaluation.

Wallis Consulting Group was hired to conduct both the pre and post telephone surveys. They achieved 500 completed pre surveys from a sample of 854 member details (a response rate of 59%). The remaining 354 did not participate in the pre survey for reasons such as not answering their phone after several attempts, and disconnected numbers.

Close to two thirds (62%, n=311) of those who participated in the pre survey were available and willing to complete the post survey. Pre survey respondents who did not participate in the post survey (n=189) were not included in the pre and post comparisons. The majority of participants were male (60%, n=188).

Results and Discussion
Of the 54 clubs represented in the analysis, 53% completed all four interventions. All clubs (100%) had displayed the beyondblue information station and conducted a local services audit, and 97% of clubs had held a ‘blue’ themed match or event. However, only 55% of clubs had members who had completed the mental health awareness training at the time of the post survey.

Qualitative analysis indicated that GSGMH had raised awareness of mental health issues among member of participating sporting clubs. One club contact spoke about the fact that
participating in the program opened his eyes to the fact that many people in the club had
direct or indirect experience with mental health issues.

“I've been amazed at how many people want to talk about it, and how many people have been
touched by it. They've been through it or they know someone – someone in their family or a
close friend”.

Another club representative indicated that their club was aware of a direct positive outcome
from their club’s participation in the mental health awareness training in terms of both
increased awareness and increased capacity to provide help:

“I had one parent go out [of the training] and say, ‘Now I know what’s wrong with my husband’. It
was quite amazing. And she followed up with it, and sure enough he was severely depressed
and she was able to do something to help him get back on track. So we had an immediate
success following the training – it was really good.”

There are also examples which indicate that GSGMH has contributed toward club
understanding of mental health issues and that this understanding has been translated into
greater support for individuals within the club. The following quotes from one of the Project
Officers exemplify this:

“[At the club’s ‘blue’ themed event, a member] got up and said, ‘I’ve suffered depression for
about five years…I needed to do this [get up and tell you all] because it will help me in getting
better. I just wanted you to know that…it’s good to have that support, and cycling really helps
me as a sport because it’s social and everything like that’”

The Project Officer went onto say that having participated in GSGMH other members now
had a better understanding of how they could help this member in the future:

“Members said, ‘There were days when he didn’t turn up to racing and we just thought, ‘Oh
well, he must be busy’, but now we know, just that phone call to say, ‘Are you ok, are you
coming out, do you need us to pick you up’”

All respondents were asked a number of questions to assess the impact of GSGMH on
knowledge about mental health issues. Each of these questions is discussed below.

Firstly, respondents were asked what they considered to be the major health problems in
Australia at present. Significantly more members in the post survey than the pre survey
raised mental health and depression as a ‘first mention’ and in the ‘total mentions’.
The portion of pre GSGMH respondents and post GSGMH respondents that reported
alcohol/drug abuse, mental health, and depression as major health problems in Australia are
shown in Figure 1.

Figure 1: Pre-GSGMH and post-GSGMH of alcohol/drug abuse, mental health and depression as
major health problems in Australia at present as first mentioned by respondent
The seven most frequently reported health issues by respondents were obesity, alcohol/other drugs, cancer, heart disease, mental health, diabetes and depression.

Respondents were asked what they consider to be the major signs or symptoms of depression. There was a general trend of more members identifying signs and symptoms spontaneously in the post than the pre survey. Significantly more members in the post than the pre survey reported withdrawal, mood swings/change in mood, and change in personality or behaviour as ‘spontaneous mentions’.

The first aim of GSGMH, was to, raise awareness of mental health issues and available support amongst members of rural sports clubs to reduce the level of mental health issues in those communities. Both the qualitative and quantitative data collected for the evaluation suggests that GSGMH can be effective in raising awareness of mental health issues and available support among members of rural sport clubs.

The qualitative interview data suggested that many clubs understood the need to increase awareness and understanding of mental health issues and enthusiastically embraced GSGMH. Moreover, there were numerous reports that the program was effective in achieving an increase in awareness and understanding. The blue rounds and mental health awareness training were highlighted by club contacts, Project Officers and Community Partners as being particularly effective in this regard. The local services audits were also highlighted as being very important given their potential to raise awareness of local sources of professional help on an ongoing basis.

**Conclusion**

Evaluation has indicated that *Good Sports, Good Mental Health* is to be having a positive impact on awareness and understanding of mental health issues in community sporting clubs.

Data collected to date suggests that the program can result in increased preparedness to talk openly about mental health issues, and for the club environment to respond with support rather than ridicule. Many people join sporting clubs for the social connection and sense of community that comes within the club environment. However, without education and understanding, mental health issues may in fact be exacerbated through lack of support by other club members. While the extent of this change from just the four interventions will vary depending on the extent of mental health capacity that existed prior to the project, it appears a heightened awareness is being achieved.

Many clubs have found that their participation in GSGMH has ignited ongoing commitment to building an environment conducive to good mental health. While further support may be required to embed sustainable changes in some clubs, GSGMH has opened a genuine opportunity to facilitate a change in attitudes and culture in the sporting club environment.

**References**

Treatment decision making for young people diagnosed with major depressive disorders: The case for shared decision making

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ABSTRACT

Introduction: Shared decision making (SDM) is a model of medical or treatment decision making that involves collaboration between a clinician and client. One way of implementing SDM is with the use of decision aids (DA), which have demonstrated effectiveness for non-psychiatric conditions and emerging evidence for adults diagnosed with mental disorders. A theoretical basis for SDM for young people has been made, yet work in this area is in its infancy.

Aim: The aim is to develop an online, evidence-based, preference sensitive DA to support young people facing a choice about treatment for moderate to severe depression.

Methods: The DA was based on systematic reviews and semi-structured qualitative interviews that were conducted with clients (n=10), caregivers (n=5) and clinicians (n=22) about their experiences and beliefs about treatment decision making for young people diagnosed with major depressive disorders. Further consultations were held with medical, consumer and caregiver experts and pilot testing completed the development process.

Results: Data from interviews demonstrated that client preference for involvement in treatment decision making for depression is not static and may vary with different clients and at different times for the same client. Caregiver involvement was seen as optional. All participants voiced a preference for interactive, evidence-based information to support decision making. Based on this and consultations with expert groups, a DA was developed and pilot tested. Clients and clinicians found the DA to be acceptable and useful, and their feedback was used to refine the DA.

Discussion: Treatment decision making in this area is a complex process that can be supported with the use of an evidence-based, preference-sensitive DA. The development of this DA contributes to the emerging field of youth SDM and can now be further tested for effectiveness. Approaches such as this DA hold the potential to improve client satisfaction, adherence and clinical outcomes.

Keywords: Depression, shared decision making, treatment decision making, patient decision aids
Introduction: Young people diagnosed with major depressive disorders (MDD) are likely to experience a range of challenges. In addition to the symptoms that are associated with MDD, young people are at increased risk for negative outcomes across emotional, physical, social, and occupational domains (1-7), including higher rates of suicide (8). Yet MDD is common in young people, with one in every five people experiencing a major depressive episode before they turn 18 years old (5, 9, 10). There are effective treatments for MDD (11), such as CBT, yet young people will also face numerous difficulties in seeking help and accessing treatment. Help seeking rates are low in this population (12-14), and a range of factors, such as stigma (15) and attitudes to treatment (16, 17), will likely lead to a delay in, or barriers to, accessing treatment (18, 19). There is a need to make the most of the opportunity that arises when a young person diagnosed with MDD does overcome these challenges and presents to a service. Treatment guidelines (e.g. (20, 21)) advocate for the involvement of young people in making decisions about treatment where possible.

Shared decision making (SDM) is a model of treatment decision making that involves a collaborative partnership between the clinician and client, who work together to make a decision that is based on both evidence and client preferences and values (22). Decision aids are decision-making tools that present the potential risks and benefits of appropriate treatment options and encourage clients to consider their preferences and values in relation to these possible outcomes. Decision aids have demonstrated effectiveness in non-psychiatric health areas (23) and there is emerging evidence for the use of SDM in adults with mental disorders (24, 25), although no studies have been conducted with young people diagnosed with mental disorders. Youth depression is an area previously highlighted as potentially suitable for the application of SDM (26).

In order to obtain preliminary data for this topic, we explored the experiences and beliefs of clients, caregivers and clinicians about treatment decision making for young people diagnosed with major depressive disorders via semi-structured interviews. Results from these data are published elsewhere (27, 28) and highlighted four important aspects of the decision-making process: 1) although a collaborative model was important to clients, caregivers and clinicians alike, experiences of this varied; 2) clients were not asked explicitly about their preference for involvement; 3) the caregiver’s role in decision-making processes should be dependent on the preferences of the young person and existing caregiver involvement; 4) there is a significant gap in the availability of high quality, evidence-based, unbiased, youth friendly, interactive, web-based information resources to support the decision-making process. Based on these data we sought to develop and field test a decision aid for young people diagnosed with moderate to severe depressive disorders.

Developing the DA for field-testing: The development of the decision aid involved drafting a prototype based on the interview data discussed above, Cochrane systematic reviews, the Ottawa Decision Support Framework (29) the International Patient Decision Aids Standards (IPDAS) (30) and the IPDAS instrument (IPDASi) (31). This prototype was then refined based on consultations with client, caregiver and clinician experts. Experts were shown the DA and asked for feedback on the content and design. Following this, the DA was field-tested in order to complete the development process, a step often either neglected or poorly described by developers of DAs (32). The purpose of this phase was to gain feedback from both parties using the DA (client and clinician) as they were actually engaging in the decision-making process. Feedback from clients and clinicians was obtained on earlier drafts of the DA, however this involved asking individuals to comment based on decisions they had made in the past. Given the dynamic nature of decision-making processes, the current field-testing aimed to acquire in situ responses to the usefulness and acceptability of the DA.
**Aims:** 1) To determine the acceptability of the format, design and content of the decision aid; 2) To determine the usefulness of the decision aid with regard to the content (i.e. information provision) and function (e.g. helping to make a decision).

**Methodology:** Setting: All participants were from either one of two services: Orygen Youth Health (OYH) and headspace Barwon. OYH is a specialist youth mental health service for young people aged 15-24 living in the northwest metropolitan area of Melbourne, Australia. headspace Barwon is an enhanced general practice service for young people aged 12-25 living in and around the satellite city of Geelong, 75kms southwest of Melbourne.

Participants: Slightly different sampling methods were used at each service. At the OYH Youth Mood Clinic, where most clients would be eligible for the study, all four psychiatrists agreed to be participants should they successfully recruit one or more clients. At headspace Barwon, two GPs who were most likely to see clients eligible for the study were nominated by the clinical coordinator, and agreed to participate should they successfully recruit one or more clients. All eligible clients were asked by their psychiatrist or GP respectively to participate in the study, and all clients approached agreed to do so, although one client failed to attend the scheduled appointment. In total, three clinicians and five clients participated in the field-testing of the DA.

Inclusion criteria: 1) Young people aged 12-25 years old who have been diagnosed with MDD and are facing a decision about treatment options for moderate to severe depression, but who have not previously taken fluoxetine; who have sufficient language skills and intellectual capacity to provide informed consent and participate; and who are not currently experiencing a psychotic episode; or 2) Clinicians of participants in criterion 1.

Ethics approval: Ethics approval was obtained from the relevant local committee (Melbourne Health Research and Ethics Committee; reference number 2009.659). Parental or guardian consent was obtained for participants aged less than 18 years old.

Procedure and materials: Medical clinicians of the two services were asked to participate in the field-testing of the DA. If agreeable, clinicians were asked to identify clients (as described below). They were also asked to act as participants in the study and provide feedback on the DA if one or more of their clients was involved in the field-testing. Rather than providing feedback on the DA for each of their clients who used the DA, they were simply asked to provide feedback at the end of the field-testing based on their use of the DA with all of their clients who had been involved. If none of the clients seen by the clinician participated, then they were not considered participants themselves and were not asked to provide feedback. A printed version of the DA was made available if a computer was not available for the consultation. Feedback was provided via a questionnaire. There was significant overlap in the items included in both the client and clinicians questionnaire, however there were some minor differences and these are indicated below as the items are described.

Clients were identified by their treating psychiatrist or GP and informed about the study. If agreeable, the researcher met with clients immediately prior to their usual appointment with the psychiatrist or GP during which a decision was due to be made about treatment for depression. Further information was provided about the study by the researcher and clients, or their legal guardian if aged less than 18 years, and informed consent was obtained. Part of the client version of the questionnaire was administered before they had the decision-making consultation with their clinician. This was so that questions relating to their ‘choice predisposition’ (see below) could be administered before they made the decision. The remaining items were administered after the consultation.
Items in the questionnaire used for both the clinician and the client were based on the Ottawa Decision Support Framework (29). Questionnaire items included items from the Control Preferences Scale (33); the Stage of Decision Making scale (34); the Decisional Conflict Scale (35); and an adapted version of the Choice Predisposition Scale (36) (for clients only). The Choice Predisposition Scale was administered before and after the decision-making consultation in order to assess whether or not a decision was made or changed, and to assess knowledge of treatment options. Additional investigator developed items about the acceptability and usefulness of the DA were also included.

Data analysis: Thematic analysis (37), was used to analyse the open-ended questions. For questionnaire items that were scored, the present study did not seek to make statistical comparisons with the data. Rather, these were used to highlight (i.e. via extreme scores) areas of the DA that need improvement. Amendments to the DA were subsequently made based on the responses.

Results: Participants: Three clinicians and five clients participated in the field-testing of the DA: one clinician and two clients from headspace Barwon and two clinicians and three client from OYH. The three male clinicians, two psychiatrists and general practitioner, were aged 27, 38 and 57 years old. The five clients, three females and two males, were aged 15, 16, 17, 17, and 20 years old. All but one was facing their first treatment decision for a mental disorder and none of the participants had a comorbid disorder.

On the Control Preferences Scale, two clinicians reported that they preferred to share responsibility for deciding which treatment is best for their clients, and one clinician reported that they preferred to make the final decision about which treatment is to be used, but that they seriously consider their clients’ opinions. Clients had a range of preferences. Two clients reported that they preferred to share responsibility for deciding which treatment is best for their doctors; one client reported that they preferred to make the final decision about their treatment after seriously considering their doctor’s opinion; one client preferred that the doctor makes the final decision about which treatment will be used but seriously considers their opinion; and one client preferred to leave all decisions regarding treatment to his doctor.

Acceptability of the DA: In terms of the design and format of the DA, all participants (i.e. both clinicians and clients) found it to be acceptable. No suggestions were made in terms of changes to layout or the use of graphics. The content of the DA also appeared to be generally acceptable to all participants. All of the clinicians rated the acceptability of each section of the DA as either ‘good’ or ‘excellent’. Clients did the same; except for one client who felt that the ‘side effects’ and ‘what matters to you’ sections were of a ‘fair’ standard (reasons for which are described below). Overall, however, all participants felt that the length of the DA and the amount of information was ‘just right’. All participants also found the DA to be ‘balanced’, although one clinician added a caveat, that it was “possible too dependant on TADS”.

Usefulness of the DA: When asked about the amount of information in the DA, all but one of the clinicians and all but one of the clients felt that it was ‘just right’. One client felt that there was too much information in the ‘side effects’ and ‘what matters to you’ sections, but he could not specify which individual items should be removed. He felt that they contained too much information, had too much writing, and that they should be simpler and easier to read. One clinician said that the ‘side effects’ section had too much information. On the relevant items of the decision conflict scale, all participants either ‘agreed’ or ‘strongly agreed’ that they 1) knew the benefits of each option; 2) knew the risks and side effects of each option; 3) had enough advice to make a choice; and 4) felt like they had made an informed choice.
In terms of the function of the DA, that is whether or not it helped clients to make a decision, clinicians all felt it was useful. One clinician described it as a “revelation” and said that it was a “very powerful educational tool that educates doctors and patients alike”. Another clinician said that it was a good “visual cue” and that “often when talking to patients it is good to have messages visually, which definitely helps to make a decision”. One client felt that it made his decision more difficult because he had to “think about it more” than if the doctor just told him what to do, but he found it very useful to see more side effects listed. The remaining four clients found it useful in helping them to make a decision. One client felt the DA was useful because it “told me more about (the decision)” and although she felt she would get some knowledge from talking with the doctor, she felt that “this gave me more”. Another client reported that the DA was useful because it “changed my mind” about the treatment option and he was “feeling more positive because my chances of getting better are higher”. Other comments from clients included that it was “good to see right there treatment options – I’ve never had it put in writing before and I like that it’s more than someone’s opinion and that I’m being told what everyone gets told”; that it was good because “it had the things that I usually tend to ask” listed; that it was good to “see side effects listed so when I take medication I won’t feel like something’s going awry” if she experiences a side effect; and that the graphs were “fun to look at and compare, they were easier to read than the percentages”.

Items on the decisional conflict scale relating to usefulness were generally rated as ‘agree’ or ‘strongly agree’ by all participants, however there were some exceptions. None of the clients felt that ‘the decision is easy for me to make’. Three clients disagreed that they were ‘clear about which benefits matter most to me’, one client disagreed that he was ‘clear about which risks and side effects matter most to me’, and was client disagreed that she was ‘clear about the best choice for me’ and felt ‘sure about what to choose’. This same client was the only participant whose level or certainty decreased slightly after using the DA (discussed below). The client clarified in the ‘any further comments’ section that this decisional conflict was present before using the decision aid; that she still felt that the DA was useful; and that the discussion with her doctor had led to the decrease in certainty, whereby she was slightly less sure about refusing medication.

Other items relating to the function of the DA included a comparison of Choice Predisposition Scale before and after the consultation. Before using the DA, one client did not know his options, and the remaining four clients reported knowing either two or three (doing nothing, counselling, antidepressant medication). After using the DA, three clients listed all four treatment options (doing nothing, counselling, antidepressant medication and both counselling and antidepressant medication). The remaining two clients reported the same knowledge as before using the decision aid (counselling and antidepressant medication).

Four clients changed their decision after using the DA to opt for a combination of both counselling and antidepressant medication, and one client decided to stay with her original decision to select counselling only. For two of the clients their level of certainty was reasonable high (80%) and did not change after using the DA. For another two, their level of certainty was lower to begin with (30% and 60%) and after using the DA they felt 100% certain about their respective choices. However, for one client her level of certainty decreased slightly, although she did not attribute this to the DA (as discussed above).

Lastly, participants were asked to provide further comments about what they liked about the DA and what they felt should be improved. Comments from clinicians included that it “gave a firm statement of consensus” about treatment outcomes, that it had “informed content at a very sophisticated level”, that it “presented facts simply and clearly” and that “irrefutable statistical facts” meant that it was a “powerful tool”. One clinician noted, however, that
familiarity was needed before using the DA in order to minimise the time it took to work through the decision. Another clinician liked that he could give the client a copy of the DA so that he “didn’t have to cover all the points” in the session, but that they could act as a “prompt” for him, which was “really good, really useful”. Clients felt that it “looked alright”, “helped doctors to explain stuff”, was “simple” and “easy to read”, that it was “good that it could make me understand more about it” and “good to see ratings of how medication and counselling can help”. Similarly, one client said she was “just happy to see a counsellor now” and now felt that “medication will help and make my life better, make me happier”. This same client reported that prior to using the DA she was worried about antidepressant medication making her “go more mad in the long run” and that being prescribed medication or seeing a counsellor would result in her losing custody of her child but that these fears had been alleviated during discussions in the ‘what matters to you’ section. One suggestion for improvement came from a client who said that she would have liked to know how alcohol would affect the medication.

Changes made to the DA based on field-testing: Overall, the data suggest that both clients and clinicians found the DA to be acceptable and useful. Aspects that could be improved, as identified by extreme scores and general feedback in the questionnaires, included the level of information included and the degree to which decisions were based on client values. Actions taken based on these data are described below. The decision aid has since been amended slightly to address these points, with some information being included in optional downloadable PDFs rather than on the web page itself, and an optional values clarification exercise being re-included as a downloadable PDF.

One issue, namely that the DA influenced the decision made, did not result in any changes. Although all clients chose guideline concordant treatment options, the DA was designed to support decision-making processes rather than influence treatment choice. It may be that the change in treatment choice would have occurred anyway without the use of the DA (i.e. after discussing treatment options with their clinician during treatment decision making as usual), however further testing using a randomised controlled trial comparing the DA to treatment decision making as usual is needed to explore this issue.

Discussion: This paper describes the development of the first publicly available DA developed specifically for youth mental health. The choice of decision to investigate, namely treatment for depression, was an important starting point due to the number of young people locally and globally who face such a decision.

The DA was informed by relevant theories and empirical evidence, and developed in accordance with international standards. Furthermore, input from clients, caregivers and clinicians was sought at salient time points in the development process. The comprehensive development process also involved field-testing with clients and clinicians, a criterion of the IPDAS (30) and item in the IPDASI (31) that is often neglected or poorly reported (32).

The DA appears to be acceptable and useful to both clinicians and clients from primary care and specialist mental health services. Field-testing was conducted with a small number of participants, however, and was undertaken to refine the DA rather than test the effectiveness of it. Additionally, the approach taken to focus on acceptability using the ODSF, does not provide data on all aspects related to feasibility, namely demand, implementation, practicality, adaptation, integration, expansion, and limited efficacy of the DA (38). Further research is also needed to explore the effectiveness of the DA in terms of whether or not it helps clients make decisions and whether it increases outcomes such as satisfaction, adherence, and knowledge about depression and treatment options. This DA adds to the growing field of youth SDM (e.g. (39-41), and offers a basis for the development of further DAs in other areas of youth mental health.
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References:
Empowering Peer Support Workers in Mental Health Service Delivery

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ABSTRACT
Studies from the USA and Australia acknowledge the unique contribution that Peer Support Work (PSW) makes to the mental health system and to the recovery of Persons With Mental Illnesses (PWMI) that are served within it. Given the paucity of literature in the Australian context, it is imperative that the challenges faced by PSWs in their role be investigated and addressed, in order to sustain and develop the existence of peer support services in Australia. The aim of this presentation is to: (1) Describe the challenges of PSW; (2) Describe strategies undertaken by supervisors to empower PSWs at three different levels (grassroots, local organisations and systemic); (3) Propose a way forward to ensure sustainability of PSW’s contribution to service provision.

Keywords: (max. 6 keywords from lists supplied for conference streams)
Peer Support Workers, Recovery, Grassroots, Local Organisation, Systemic
BACKGROUND

Moving away from a deficits-approach, Anthony (1993, p. 527) describes recovery as “...a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and a contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.” Mead & Copeland (2000) suggest that peer support is a key component of recovery as it holds negligible assumptions about a person’s capacities and limitations, and avoids hierarchical relationships between health care providers and patients.

Studies from the USA and Australia acknowledge the unique contribution that Peer Support Work (PSW) makes to the mental health system and to People with Mental Illnesses (PWMI) that are served within it. Not only has PSW increased service reach to those with longer term needs and those who have not accessed the mental health system (Hodges, 2007; Lyons, Cook, Ruth, Karver, & Slagg, 1996), PSW has also been found to be valued by the recipients of the service (i.e.: Peers) for its client-centred approaches (Paulson et al., 1999). However, a number of challenges have been documented by American authors that potentially threaten the existence of this service if left unaddressed. These include: role confusion (Mowbray, Moxley, Thrasher, Bybee, & Harris, 1996); strained relationships between staff without a mental illness and PSWs (Dixon, Hackman, & Lehman, 1997); and the lack of career progression (Chinman et al., 1999).

AIMS

Given the paucity of literature in the Australian context, it is imperative that the challenges faced by Peer Support Workers (PSWs) in their role be investigated and addressed, in order to sustain and further develop peer support services in Australia. The aim of this paper is to: (1) describe the challenges of PSWs; (2) describe strategies undertaken to empower PSWs; (3) propose a way forward to ensure sustainability of PSW as a profession.

METHODOLOGY

This study is undertaken as the first phase of a larger study designed to investigate how Peer Support works for people recovering from a mental illness. Twelve managers, supervisors and educators of PSWs from a combination of non-governmental and public health sectors were interviewed. The interviews were digitally recorded and transcribed. The author then reviewed the transcripts and sent it back to the interviewees for review. A thematic analysis of the interview data together with documentation from various organisations and policy documents was performed using NVivo 9. These initial themes were then member checked with two original participants, from a public health sector and a non-government sector respectively.
RESULTS AND DISCUSSION

Challenges of PSW

Although the challenges to PSWs in Western Australia are aligned with existing literature, it is observed that these challenges appeared to come from participants of the public sector, indicating that the growth and acceptance of PSWs in mental health service provision has been swifter in non-governmental sectors compared to public sectors. According to Middleton (2004), a number of factors contributes to a resistance to change in such organisations. These include: stigma, tokenism, negotiating the complexities of the mental health system and an operation within the medical model (in which PWMI are obliged to participate in their treatment). Such resistance to change has been reflected in hostility from staff, professionally inappropriate behaviours and tokenism, which was expressed in a number of ways.

**Hostility from staff.** Managers have described hostility from staff without a mental illness, reflecting the stigma that PWMI tolerate within the mental health system. Jenny (pseudonyms are used for participants), in her account, describes segregation between staff without a mental illness and PSWs in their daily interactions:

“… it is still a ‘them and us’. Well it’s still symbolic and we can take our consumer reps when they sit in the kitchen and make a cup of a coffee alongside staff and nobody bats an eyelid. But down there [another service] I’ve had people come and say, “Can you not let them into the staff room?”

**Professionally inappropriate behaviours.** There also appeared to be a lack of awareness amongst staff in relating professionally to their colleagues who were PSWs. Petra gave examples of how PSWs were treated amongst clinical staff:

“…they ask… inappropriate questions to peer workers, like you know whether they are taking their meds, or are they a bit elevated today because they seem so lively, and you know things like that.”

**Tokenism.** According to the Middleton (2004), tokenism occurs when consumers are involved in jest, without support from the organisation or are employed in part-time, low paid and low status positions within the organisation. This was manifested in a number of ways such as the lack of referrals, refusal of access to notes, poorly written job descriptions and being nominated for tasks that are not within their scope of responsibility. One participant commented that staff acted as gatekeepers, preventing PSWs from receiving referrals, or refusing their access to notes. This can be attributed to wider organisational tokenism, which created an attitude of suspicion amongst staff. This was aptly described by her:

“So there was all this gate keeping and again this comes back to how the programme is set up and...Unfortunately because this was set up in a hurry, there was no kind of community development approach in developing the programme. What inadvertently was created then was an attitude by staff of suspicion...” (Petra)
The effects of organisational tokenism not only affected staff without a mental illness but also filtered down to PSWs, causing role confusion and an undervaluing of their role. This was reflected in poorly written job descriptions and being nominated to take on responsibilities that were not within the scope of their responsibility. As described by Petra:

“… their JDFs were just so poorly written, I mean they had things in the JDF like, ‘will provide comfort to the patients’. (Emphatically) What does that mean? I mean some people were horrified, and deeply offended because they obviously felt that was a very kind of personal way of writing a JDF, and the other people were just intellectually perplexed and would say well I… what does that mean comfort? You know am I supposed to rub their feet or… ‘What is that give them a cuddle if they get upset, what do I do?’ “

**Strategies undertaken to empower PSWs**

There are a number of strategies that occur at various levels to empower PSWs. At its grassroots, the support of supervisors for PSWs plays a pivotal role in empowering them to operate within various teams. This however needs to be supported at a local organisational level through the backing of the highest level of management; and organisational policies and procedures. At a systemic level, PSW is supported by higher level governance and policies that preside over the direction of service implementation in local organisations.

*At the grassroots level.* Supervisors described a number of strategies that empowered PSWs to operate within the organisation. This included locating themselves in the same geographical space; being a bridge to the team; affording both clinical and emotional support in supervision; and providing flexibility around their work arrangements. The first two strategies that are described pertains more so to the public sector, which appeared to combat staff suspicion and decrease hostility towards PSWs. The last two strategies were undertaken across public and non-governmental sectors, conferring greater autonomy in their mode of practice.

Sharing the same geographical space communicated a sense of availability to the Peer Workers.

“But what you do have to do is be there and be available to the peer workers. So we have an office that’s smaller than this actually and we share it. So I’m sitting with them and that was new as well. …” (Petra)

Supervisors in the public sector mostly, helped to facilitate the acceptance of the PSWs amongst teams, by preparing the team for the PSW’s entrance into the team, and bringing the PSWorker to multidisciplinary meetings to personally introduce the PSWorker to the team. As Petra describes:

“And so as I said I would take them to the meetings and what have you. But I would also try to send emails to the medical offices and the psychiatrists that say look, this person starting on this day, I would like them to come to the meeting I hope that’s
okay, I hope you sort of take them under your wing and you know, make them comfortable in the meeting and so on; so just to forge that link in a way…”

According to Huffine and Clausen (1979) PWMI experience anxiety and lack of confidence in their early days of their return to work. However, the greater their ability to perform in their work, the greater the reduction of self-doubt. To this end, supervisors not only offered support with clinical issues, but also offered emotional support even as the PSWorker grew in confidence within their roles. Supervisors (being mental health care professionals themselves) also expressed clarity about the boundaries between giving emotional support and administering therapy to PSWs. As Jenny aptly describes:

“What really worked for [D] … when he first started that [P] the social worker would regularly go with him on visits …, they would drive and sit on the beach and just talk through everything so he managed to off load how it was going for him. … so it was that kind of really emotional debriefing as well as the practical stuff… they all do need somebody watching what they’re doing, not in a monitoring way, but just being with them and walking beside them until they become comfortable with it.”

Thornicroft, Brohom and Lewis-Holmes (2008) recommend that commensurate with physical adjustments for people with physical abilities at the work place, reasonable adjustments should be made for some PWMI. O gives an example of a reasonable accommodation in her team:

“I built in quite a lot of flexibility so though she came to work …, she needed to go and have a bit of a lie down in the afternoon. So we had a like a roll up thing there so she did book off for you know, a few hours and go and have a bit of a sleep. She was normalizing her sleeping pattern … If you are well enough to drive then you can do a part day and you need a bit of a break in the middle of the day then I’ll accommodate and support that.”

At a local organisational level. A number of approaches were described by interviewees at a local organisational level, that aligned itself well with Johnson’s (1990) argument that a range of mechanisms from policy statements to training, to adapting shared symbols are needed to reinforce a new vision at a local organisational level. This encompassed: the support of leadership; consistent adaptation of certain symbols across the organisation and having policies and procedures that safeguard the role of PSWs.

A number of participants from public and non-governmental organisations reiterated that the support at the highest level of management was important in helping to prepare the organisation to embrace the new vision of recovery and with that, the introduction of PSWs. In Jenny’s words:

“You know, leadership is so important. The fact that we’ve got managers who really believe in peer work…. I think the services can do that sort of thing [have consumer involvement at other levels]. It builds the culture of respecting, it’s not an ‘us and them’ it’s they’re expert so we can work alongside.”
Another participant, S recounted an example of how adapting a shared symbol helped to reinforce a recovery vision at her organisation. In some cases, the Ulysses agreement was seen as a form of discrimination as it mainly applied to PSWs only in organisations. In this case, there were two shared symbols that were adapted to reinforce a recovery vision: the use of a well-being plan in place of a Ulysses agreement and the use of the term ‘mental distress’ instead of ‘mental illness’. S recounts:

“… we identify the signs that they are becoming stressed, so we tend to in most situations use the word mental distress, because we see mental illness as being mental distress rather than seeing it in those illness terms. And so in my well being plan it talks about what I see in myself when I am, what are the signs I’m becoming stressed, what are the signs I’m becoming more stressed and what are the signs I’m not coping; and so that’s the same as the peers.”

Lastly, having policies and procedures that specifically highlighted the role of PSWs not only reinforced the vision of recovery, but empowered PSWs to operate autonomously in their area of responsibility. For example, one organisation’s protocol in developing a work plan with a peer reads as follows:

“The PSWorker aims to assist peers to develop a vision for recovery and practice new skills that support recovery and enable the peer to achieve a satisfactory and meaningful life... the focus of work may include:

- physical and mental health and wellbeing;
- community connecting;
- establishing and maintaining supportive social networks;
- accessing recovery tools such as WRAP.”

At a systemic level: Other documents also highlight the support that wider higher level governance and policies have for Peer Support programmes, giving PSWs a place within the mental health system. For example, the Mental Health Commission Document (2010, p. 43) states under its eighth action area that “peer support and mentoring [be seen] as an accepted and valued part of mental health support and services.” However, the current mental health system is disadvantaged by the lack of strong stewardship, accountability and coordinated funding resulting in an inconsistent implementation of state and federal policies across services (Townsend, Pirkis, Pham, Harris, & Whiteford, 2006).

CONCLUSION

By analysing a combination of interview transcripts and documentation, the current study has explored the current challenges to PSW and strategies to empower PSWs in mental health service provision. The analysis highlights the need for a cultural shift away from a traditional medical model which focuses on the illness to a recovery model which takes a strengths-based approach to meeting the needs of PWMI. Whilst the current appointments of the Commissioner for Mental Health, and the establishment of the Mental Health Commission appear promising, a stronger governance incorporating all levels and sectors of the mental health system needs to be developed, in order to provide a continuity of care that is specifically targeted at facilitating the recoveries of the PWMI that are served within it.
REFERENCES:


Impact on adult children caring for elderly parents with a long-standing mental illness

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Abstract
Introduction: This research contrasts the experiences of long-term carers of elderly parents who have had a long-standing mental illness and first-time carers of parents who have become mentally unwell in old age. It was hypothesized that the children of elderly parents with a long-standing mental illness have differing needs when faced with the caring role compared to first-time carers of elderly mentally ill patients.

Method: Using a qualitative research methodology and interpretive perspective, eight carers were interviewed using a standardized questionnaire from which salient issues were drawn and analyzed.

Results: Long-term carers faced issues including a longer duration of care-giver stress, early entry into adult responsibilities of caring, frustrations concerning lack of recognition from mental health services and cumulative stress affecting long-term carers’ significant relationships and health. First-time carers sought earlier access to mental health services, specialist information about mental health issues and coping strategies for the care-giving role.

Conclusion: It was found that both sets of carers (long-term and first-time), irrespective of the duration of their caring experiences, shared complex and competing demands on their physical and emotional resources. All carers were able to identify ways to improve support to improve support to children caring for ageing mentally ill parents.

Key Words: carers, impact, mental illness, elderly parents, adult children
Past research has identified issues faced by carers concluding that they are subject to overall poorer physical and psychological health.\textsuperscript{1, 2, 3, 4, 5} This is the case even where carers report positively on the experience of caring.\textsuperscript{1, 4} An expanding body of literature now also documents the difficulties encountered by children growing up with parents who are mentally ill, citing poor physical and psychological outcomes for children as they move into adulthood.\textsuperscript{6, 7, 8, 9} There is however a paucity of research examining the experiences of adult children who care for an elderly parent with a psychiatric illness, in spite of the numbers of children engaged in parental care.

With better treatment and support, people with mental illness are living longer. By 2041 it is estimated that 500,000 people will be suffering dementia. As a result, significant numbers of children will be growing up with a parent who has mental illness and adult children will be called on to provide care for parents who will develop a mental illness in later life. It is essential that research be undertaken to examine the longitudinal impacts on children living with parents who have a mental illness, as well as the needs of adult children who are called on to support their parents for the first time in later life.

With this in mind we made contact with 8 adult carers of elderly clients who were being case managed by our aged persons mental health service. A questionnaire formed the basis of a semi-structured interview designed to explore the impact and experiences of carers. It also asked about carer’s perceived needs and suggestions for models of service delivery. Four carers were aged 40-50 years and four were over 50 caring for parents aged between 76 and 89 years. Only 1 carer was male, 5 were married, 2 were divorced and 1 single. Three of the carers were the ‘only’ child, 1 carer was a daughter-in-law and 4 carers had four or more siblings. Three of the carers were in full-time employment, 3 were not employed and 2 were employed part-time. None of the carers received any Centrelink carer-related entitlements. Three of the clients were divorced, 3 were widowed and 2 were married, 2 were diagnosed with mental illness before the age of 18, two between ages of 40-55, one between 65-75 and three after the age of 75. Three of the carer’s were under 11 years when their parent became unwell, two were in their 20’s, two in their 40’s and one was over 50. Only one carer reported good knowledge of mental illness and having been given adequate information about their parent’s illness at the time of diagnosis.

Carers all reported that caring for a parent had a direct bearing on their own mental health and all described other significant impacts in terms of family and relationships, social connectedness, self esteem, personal security and employment or career aspirations. The long-term carers described physical, emotional or psychological stresses that they related directly to their caring roles with a parent with mental illness. One carer reported feeling unable to cope and four carers had sought counselling. Strategies like limit-setting, yoga, meditation, exercise, development of positive social networks and spirituality were used as means of reducing the burden of caring.

Overall there were more similarities than differences between the needs and experiences of the carers. A high incidence of “loyalty” was expressed as a motivator for caring for a parent, with six carers identifying this as a motivator followed by determinants of “love”(5) and “choice”(5). At the same time, six carers reported that their relationships with their spouse and siblings had been negatively impacted by care-related responsibilities. Interpersonal distress occurred as a result of competing pressures between care-giving and family demands. Tensions resulting from the difficult behaviour of an unwell parent and the lack of
appreciation for the caring role led to depression, guilt, anger, personal distress and feeling of manipulation and not being appreciated. In general the long-term caring role (compared to short-term carers) was perceived as a much more demanding role due to the length of years of caring and the constant emotional strain.

The need for timely diagnosis, information and counselling about mental illness was suggested at the time a parent became unwell, to be followed by mentoring, community support and courses about coping in the longer term. More than half of carers preferred programs concentrating on skills based workshops such as stress management, coping with difficult behaviour, medication and its side-effects, issues for grandchildren and future planning directives. Some carers did not have the emotional resources to deal with long, drawn out therapeutic endeavours but preferred pertinent information, reinforcing the idea that information empowers and brings a sense of personal mastery over stressful situations. Six carers wanted to have direct contact with the treatment teams in the form of family meetings. Five carers believed there was a need for individual counselling from a health professional at a time of personal need. At other times there may be a need for tailored family interventions or group therapy where participants can be heard, validated and understood. The therapeutic gain from verbalising sentiments is well known and utilising support groups offered by mental health services is another positive alternative.

This qualitative research project relied upon extensive narrative feedback from a small group of individuals engaged in the care of mentally ill parents. What emerges is that adult child carers, irrespective of the duration of their caring experiences, have complex and stressful lives, and spend a good deal of their time trying to negotiate competing demands on their emotional and physical resources. They largely do this with minimal help from wider formal support networks. As adult carers for a parent, many of the experiences of day to day activities overlapped, but were often contrasted by the duration and intensity of the experience of caring. Long-term carers were able to reflect on their early experiences and in what ways these impacted on their current lives. All carers in the study reported dilemmas that reflect the chronic, fluctuant nature of mental illness itself. All carers described stresses arising from undertaking ongoing supervising, monitoring and decision-making roles, and from witnessing parents’ distress (due to illness, self-injury or treatments). All carers presented as being well organised, vigilant and available to their parents. The majority had limited formal support in the caring role and had to juggle the competing demands of their family relationships or responsibilities.

Partners and children were often the primary support to carers, although many reported there to be ambivalence from these sources as well. Issues like being physically or emotionally exhausted and unwell emerged consistently as did elements of frustration about negotiating an often complex and sometimes even hostile health system.

In research by Veltman, Cameron and Steward(2002), caregivers felt “let down” by the mental health system feeling that they found it “adversarial” rather than one of “advocacy”, often reinforcing the negative view of caring and failing to express support for the positive aspects of caring. Such sentiments were echoed by the carers in the present study. Most keenly expressed throughout the research was the call by carers to be “believed” and “listened to”. This sentiment was regarded not so much about their needs as carers, but was more about being treated respectfully and as competent people asserting their concerns about their parent’s needs. Even as a small sample, their voices were loud and often unison
in expressing the difficulties and joys of being a carer of a parent with mental illness. Detecting and appropriately responding to carer’s vulnerabilities and strengths in a sensitive manner remains an essential priority for mental health practitioners and mental health services.

References


Abstract: Measurement of patient outcomes is an integral part of mental health service evaluation, as well as guiding clinical practice to ensure best outcomes for patients. Moreover, carers have long held a need for a voice in care outcomes. Despite their existing numerous tools for quantifying patient functioning based on clinician assessments or self-reports, there is a serious paucity of tools available for the carers of patients to appraise their functioning. Collateral information is well recognised as being integral for assessments of patients, but there are very few structured systems for assessing patients based on the perceptions of carers. This is despite the usually greater lengths of time carers spend with patients than clinicians.

We describe a tool developed for use in a community aged care psychiatric service, which involves four sections - a global impression of patient progress, a scorable checklist of patient functioning in multiple domains, a qualitative section for identifying the most pressing concerns from the carer’s perspective, and an open-ended feedback on treatment to date.

In this pilot study, we validated the tool against a well-recognised clinician assessment tool (The HONOS-65), and found a fair correlation.

This tool has potential for use in community aged care psychiatric services, as it provides a framework for communication of concerns, assists in prioritising care and adds value to clinician treatment plans, as well as providing another dimension to assessment of the patient while empowering carers in care participation. Practical implications of its use, limitations and potential for modifications are also discussed.

Introduction
Patient care is dependent on three crucial social factors – patient access to medical services, the patient’s occupation and activities, and their social milieu, which principally involves the carer. Carers play a vitally important role in supporting family members, friends and neighbours to live at home and remain connected to their communities.

Australian legislation has been enacted to highlight and acknowledge the role of carers (as in the Carer Recognition Act 2010 (NSW)). This legislation aimed to increase the recognition and awareness of the role carers played in providing daily care and support to people with disability, medical conditions, mental illness or who were frail and aged. According to section 5 of the Act, a carer is defined as: “an individual who provides personal care, support and assistance to another individual who needs it because that other individual: (a) has a disability; or (b) has a medical condition (including a terminal or chronic illness); or (c) has a mental illness; or (d) is frail and aged”. An individual is not a carer in respect of care, support and assistance he or she provides: (a) under a
contract of service or a contract for the provision of services; or (b) in the course of doing voluntary work for a charitable, welfare or community organisation; or (c) as part of the requirements of a course of education or training.

The Act continues to state that carers were to be considered as partners with other care providers in the provision of care, and acknowledged the unique knowledge and experience of carers.

Despite a level of regard for the role of carers that has reached legislative recognition, there is a surprising paucity of structured means of engaging them. Benbow (2012) has reviewed a range of models of carer participation which emphasize collaboration and partnership.

One means of engaging carers is to actively and routinely document their perspectives on patient care and to incorporate these in care planning which is currently driven by clinician assessment, at best informally guided by adhoc discussions with family members. The shortfall of having structured functional assessments that are only clinician-based is that they only provide for 'snapshot' assessments of patient (during time of interview) and therefore can not be comprehensive. Carers are better placed to identify the care needs of patients due to their intimate knowledge of the client and their history and their daily contact, information which can assist to provide a more comprehensive picture of the client's current functioning, and thus provide more targeted and appropriate information. Most importantly in terms of realistic goal setting and recovery-focused care, carers have the best understanding of the patient’s optimal or baseline functioning.

We furthermore considered that there is a specific need for carer assessments particularly for older psychiatric community patients. Carers of older patients tend to have at least a moderate level of contact and provide some form of care assistance, and therefore can better evaluate their day-to-day functioning.

A number of studies have considered the value of the information that is obtained from collateral sources in dealing with a significant range of adult physical and mental health problems (Achenbach et al, 2005). Collateral information is particularly important for patients with cognitive impairment, impaired insight or physical deterioration, all three of which are necessary concerns in the older mental health patient. For example, Jorm et al, 1997 showed that collateral information was as accurate as brief cognitive testing as a screening tool for dementia and argued for its use routinely.

The role of carer or other collateral information in the clinical monitoring of a person with a known clinical history (ie as opposed to assisting with diagnosis) has received much less attention and there is comparatively little information in the literature about its use in this way. Brigidi et al, 2010 compiled an Older Adult Behaviour Checklist (OABCL) to identify discrepancies between informant and self-reports to assist clinicians pinpoint areas for further evaluation and intervention, however this consisted of 113 items and is based on clinician interview of carers, not intended to be filled out by carers themselves. Otherwise, a literature search using the MeSH terms Aged Care, Collateral Sources, Clinician, Depression, Carer, Carer Burden, Diagnosis, Treatment and Monitoring identified no studies that had developed a tool comparing Carer and Clinician assessments.
We therefore aimed to design and evaluate the role of an outcome measure based on
carer assessment of the patient against existing clinician-based scales for use with
ambulatory community patients. It was hypothesised that the outcome measure would
have good correlation to an existing scale, would be acceptable to carers, it would
provide useful qualitative data, quantify the level of concern in community, and
supplement the clinician treatment plan.

Method
The study was undertaken in a multidisciplinary old age community mental health team
that provides extended case management to patients over 65 with mental health
problems in a large metropolitan region in Northern Sydney (LNS SMSHOPS). The scale
was developed to try to address the demands of extended case management and
lengthy engagements with patients.

The Carer Appraisal Scale (CAS) was designed to be brief and simple to administer, and
items chosen to assess key symptoms, signs and behaviours which have been the focus
of well-recognised and validated clinician-based performance scales. The scale was
piloted with 23 consecutive patient and carer dyads, with consent being obtained from
both patient and carer.

The scale has six sections.

Section 1: The carer is asked to quantify a broad impression of the patient’s overall
progress on a 7-point likert scale, based on a similar concept as that used in the
Clinician Global Impression Scale (Guy, 1976). A 2 week period was chosen for a
consistent assessment period, in line with time period used for other scales such as the
RUG-ADL (Fries et al 1994), HONOS (Wing et al, 1998) and Kessler (Kessler, 2003)
scales.

Section 2: An 18 point checklist, using a likert scale of 1 to 4, from “Not at all concerned”
to “Very concerned”. We felt most of the items from HONOS best identified the features
of patients that we wished to track, however (specific to older adult mental health
patients) we had a specific interest in evaluating patient sleep (something few clinicians
are able to first-hand assess, and an item carers are uniquely capable of assessing). We
also wished to have two separate items for activities of daily living (ADLs), one
specifically for instrumental ADLs, for higher sensitivity to patient functional impairment.
The term “concerned” was chosen as being least likely to cause confusion with carers,
and a decision was made not to add any qualifiers to detail for the separate items, in
order to generate a simple scale that was easy to fill out. This section is scorable, with
each item scoring from 1 to 4, leading to a minimum score of 18 and a maximum score
of 72.

Sections 3-6: These are qualitative open-ended questions, to allow carers the
opportunity to communicate anything else they wish to. The first question explored
changes in the patient, which may not have been covered from the preceding checklist
in sufficient detail. The next question aimed to determine the carer’s agenda and to
assist in identifying if the treating team’s priorities are the same as the carer. Section 5
was designed for service evaluation, to get feedback on interventions the team had
already implemented. The last section was to allow the carer to document anything else
they wished to.
Analysis
The validity of the 18 item checklist section of the CAS was assessed by correlating items with corresponding HoNOS assessments completed by Clinical staff of the Aged Care Mental Health Team. The data was analysed to assess the extent of agreement between the Carer and Clinician scoring of the CAS. Cohen’s kappa (k) was calculated using both an equal (linear) weighting of differences and a second (weighted) scale that multiplied the contribution of errors in scoring by 1.25, 1.5, 1.75 and 2.0 for discrepancies of 1, 2, 3 and 4 respectively. Ethics approval was obtained from Northern Sydney Local Health District Human Research Ethics Committee.

Results.
Of the 23 scales offered, 3 scales were declined by the patient being unwilling to allow their carer to complete the scale. Out of the 20 scales filled out, 13 were completed by a son or daughter of the patient, 6 were completed by the patient’s spouse, and 1 completed by a sibling. 15 were completed with giving the form directly to the carer, and 5 were completed over the phone.

There was no negative feedback regarding the form. Five carers reported specifically positive feedback, grateful for the opportunity to contribute in a more concrete fashion to their loved one’s care.

We were surprised at the lengthy responses to the qualitative questions. 19/20 carers completed Question 3 (Changes noticed), 17/20 completed Question 4 (Important Issue), 12/20 completed Question 5 (Team Intervention)^, and 5/20 completed Question 6 (Any other comments).

Of the 18 checklist items in section 2 of the CAS, 16 of them correlated with HONOS Items. 20 CAS forms were completed in full by the carers of clients of the LNS SMSHOPS. There were no missing data items on the CAS and no responses that fell outside the scoring format as outlined above.

The series of 20 CAS’s yielded the following data matrix:

<table>
<thead>
<tr>
<th>Carer score</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>108</td>
<td>27</td>
<td>13</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>31</td>
<td>14</td>
<td>10</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>26</td>
<td>9</td>
<td>12</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>9</td>
<td>6</td>
<td>15</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

The linear kappa value κ(l) was 0.0156 (95% CI -0.03 to 0.06) and the weighted kappa value κ(w) 0.116 (95% CI 0.06 to 0.17). This indicated a poor level of agreement between Clinician and Carer in the overall scoring of the CAS with the linear statistic (where all differences are penalised equally) being no better than that which would be expected by chance (Altman, 1991). The striking anomaly in the data is the number of times where a Clinician rated a score as 0 when the Carer rated the same item as 1 (108 of 320, or 33.8% of all matched
responses). If it were to be assumed that a Carer rating of 1 (minor or sub-threshold problem) and a Clinician rating of 0 (no problem) could be taken as an equivalent measure of the clinical feature in question, then the re-calculated weighted $\kappa(w)$ of 0.276 (95% CI 0.22 to 0.33) now indicates statistically significant “fair” inter-rater agreement.

**Discussion:**

We hypothesised that the outcome measure would, have good correlation to an existing scale, be acceptable to carers, would provide useful qualitative data, quantify the level of concern in community, and supplement the clinician treatment plan.

Contrary to our hypothesis, the scale did not correlate with an existing clinician-based scale such as the HONOS. However, in the absence of any current generally accepted ‘gold standard’ for carer-based assessments of patients and thus any comparable measure to validate this scale against, it is likely that a clinician-based scale was not the best proxy for doing so. Yet, the exercise of evaluating how this carer-based scale performs against a clinician-based scale yields interesting insights into not only the performance of the scale, but also the nature of carer versus clinician perceptions of patient care.

We first noted that carers tended to be overall more concerned than clinicians. For example, patient functioning in an area which would be reported as “no concern” under HONOS instead received a “slightly concerned” under our scale. When corrected for this discrepancy, we found that there was now a fair correlation between the CAS’s report of the patient, and the HONOS score for the patient. This possibly reflected the different backgrounds of the scorers – as mental health clinicians, we were experienced in dealing with various levels of pathology and were used to assessing patients in comparison to other afflicted individuals. However carers could conceivably be comparing their loved one against their earlier functioning – and therefore still having concerns over particular areas that were part of normal ageing, or minor deteriorations when compared to the patients’ previous high level of functioning. Cultural factors also may have a role, as it may reflect a more protected community that is unused to significant levels of mental health pathology.

By completing this scale, there were several ‘hidden’ pieces of information derived from it that we did not initially anticipate. We found, for example, that it was useful to know whether the scale would be completed. We did not (in our experience) find a situation when a carer did not wish to fill out the questionnaire, but patients who appeared to be engaging well with us were, as a result of refusing to allow carers to complete the questionnaire, discovered to be significantly socially isolated and unable to use their carers as resources.

In terms of carer acceptability and practical usage, the scale functioned very well, with a high rate of compliance and ease of administration. Although not initially designed for this purpose, we discovered that it could be implemented easily over the telephone. When completed by the clinician managing the patient, it provided rapid feedback about recent interventions and also assisted with optimising care. We had some concerns about whether there may be opposition to the scale based on perceived dissatisfaction with individual clinicians involved in care, but clinicians generally found that the scale delivered an impression of evaluating the service as a whole, not any individual clinicians. This further assisted with encouraging the concept of team management of
the patient, rather than individual clinicians. It could also be practically administered multiple times during follow-up to assess patient progress and management planning.

Some practical limitations with the scale included identifying when the scale should be given, and this is likely to vary with the service that considers using this scale. An obvious issue is that many patients do not have carers (at least, those who fit the Carer Recognition Act criteria). The term ‘team’ is problematic as carers often conceptualise all medical caregivers as being part of the same ‘team’, which the clinicians may not concur with. By providing this scale to the carer of the patient, it means that the feedback is not anonymous with regards to the service as a whole, which limits the usefulness of the feedback.

Problems with this evaluation include the lack of validation against an appropriate gold standard, given the unique nature of this scale. It was also tested in a very circumscribed area of Sydney with a homogenous middle class population or predominantly English-speaking background. Clearly consideration and adaption to the needs of those of culturally and linguistically diverse backgrounds is needed. At time of implementation, there were few disengaged carers, although this certainly could be an issue with longer implementation. There was a possible selection bias in how clinicians approached the carers of patients, in that this was a non-random convenience sample of carers.

Potential for modifications and future research
There may be a role to having the scale given by a non-managing clinician, to improve the quality of service evaluation, yet there is definite value in encouraging an interchange between carer and treatment team. The word ‘team’ could also be changed to the name of the specific service using the form. We also considered that a different version of the form to be given at initial presentation may be of use.

With regards to further research options, it would be useful to see how this form would function against carers utilising the HONOS directly (although attempts to try to have carers complete HONOS have been aborted due to complexity of the scale). It would also be interesting to see how it functions against the OABCL as the nearest existing alternative.

Declaration
This study was completed as a Quality Assurance study under governance of Royal North Shore Hospital Ethics Department.
No funding has been provided for this research and the authors have no conflicts of interest. The scale is released for use in the public domain.

Thanks to Associate Professor Carmel Peisah, Ms Anthea Johnson, Dr Ritesh Kumar, Ms Veronica Cooper, The Royal North Shore Hospital Aged Care Department

References:


Appendix: Carer Appraisal Scale

Carer Appraisal Scale

Date: 

1. How do you feel ___________ has been in the past two (2) weeks? (Please tick)
   - Present State

<table>
<thead>
<tr>
<th>Worst Ever</th>
<th>Much Worse</th>
<th>Worse</th>
<th>Little or No Change</th>
<th>Better</th>
<th>Much Better</th>
<th>As Good as they can get</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>

2. Please tick how concerned you are with the patient’s functioning in each of the following areas:

<table>
<thead>
<tr>
<th>Area</th>
<th>Not at all concerned</th>
<th>Slightly concerned</th>
<th>Moderately concerned</th>
<th>Very concerned</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Depression or Low Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Sleep</td>
<td></td>
<td></td>
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<tr>
<td>4. Appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Concentration &amp; Memory</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Seeing / Hearing / or Believing things that are not real</td>
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</tr>
<tr>
<td>7. Trying to harm themselves</td>
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<tr>
<td>8. Aggression</td>
<td></td>
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<tr>
<td>9. Wandering</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>10. Alcohol or Prescription Drug Overuse</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>11. Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Physical Health</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>13. Mobility</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>14. Interacting with Family &amp; Friends</td>
<td></td>
<td></td>
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<tr>
<td>15. Shopping, finances &amp; using the telephone</td>
<td></td>
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<tr>
<td>16. Toileting / Self-feeding and Dressing</td>
<td></td>
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<td></td>
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<tr>
<td>17. Living in a clean place</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Hobbies &amp; Pastimes</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

3. What changes have you noticed with the patient?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

4. What is the most important issue you would like the team to focus on at this time?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

(Please Turn Over)
5. Any comment on interventions the team has implemented?


6. Any other comments:


- Jymenina (2013), developed with assistance from LNS SMH 50 P
ABSTRACT

Action Intelligence (AQ©) demonstrates the importance of giving the best attention to our elders. Attention to behaviours that reinforce and reward improved responses, that identify and celebrate strengths and contributions by the elderly in low care residential facilities. New meaningful activities give purpose for living, effective daily involvement, services with compassion, identification of personal interests and capacity to contribute. Maintaining and restoring past adaptive behaviours in the aged is a social responsibility. Evidence based case studies will be provided supporting the CRAFT Principle of Behaviour. Action Intelligence focuses on a new era of heavily rewarding right responses in bringing individuals into a meaningful quality of life. New actions by the elderly will ensure new ways of feeling and thinking.

Keywords    Action Intelligence  Positive Actions  Elders Social Responsibility  Strengths

Action intelligence is founded on the power of positive action (Kennett, 2012) and the importance of individual responses focused on the best attention to behaviours that reinforce and reward effective and improved behaviours. The paradigm is relevant to all social engagements. The application of AQ is founded on the P-CRAFT principle (Constant Reinforcement of Positive Action, elicit Positive Feeling and constructive and Adaptive Thinking).

Action Intelligence demonstrates how effective professional actions are when the best attention is given to clients, our elders. The power of positive action focuses on increasing happiness today practising the principles of normalization (Wolfenberger, 1972). The daily attention to inappropriate labelling and normalization was abandoned in the 1970’s. Aged care may relate to out-of-date services. The term must be services for the elderly, our elders a respect given by the aboriginal culture and many Asian cultures. Reference is made to aged nursing homes reflect a medical model as if the aged are a hospital setting rather than sustaining normality, reflecting their past lifestyle of normal living. Staff are predominantly nurses and nurses aides that focus on medical services rather than on total services to the overall needs of the elderly and too frequently services are reduced to showers, dealing with incontinence, meals and medication.

A comparison is made with the service of individuals with mentally retardation in the 1970’s, who required 24/7 care for their limitations and for security. During the 1970’s a new focus was on Adaptive Behaviour. Currently, new actions must focus attention given to the care, service and love of our elderly. Adaptive Behaviour involves services to the elderly focusing on the application of the principles of normalization.

1. **Independent Functioning** (critical community survival demands);
2. **Personal Responsibility** (assuming individual responsibility, including decision making); and

3. **Social Responsibility** (responsibility as a member of a community by demonstrating appropriate and hopefully effective behaviours in line with group expectations. (Kennett, 1977).

New positive actions change behaviours positively. Facilities for functioning Elders especially in low care 24/7 homes must include opportunities to demonstrate individual strengths, interests, decision-making and meaningful daily living. Such experiences reduce the onset of Alzheimer’s Disease. At time of admission professionals needs to identify strengths and ways of contributing to their new family community, ensure respect for important aspects of independence, sustain dignity, utilize and optimize social competences, and insist on social responsibility.

First experiences and encounters are powerful influences on behaviour (Kennett, 2012). The first day in residential care is a major and important event in the life of an elder. Maybe collaborative assistance would put action intelligence into constructing an Elder’s Strengths, Interest and Contribution Scale.

Numerous case studies exist. At a recent workshop I conducted this year a fellow psychologist gave an excellent example of the need to identify strengths. He visited a residential facility for the elderly and was told “Don’t waste your time talking to say, Mr Brown, as he is rude, abrupt and will not communicate”. He took action and was rebuffed on two occasions. Following my “You only fail when you fail to persist” approach he persisted and on the next visit greeting Mr Brown with “You seem to be interested in ships, as you have a number of books on ships.” Mr Brown replied, “Look at the books and who is the author.” My fellow psychologist said, “Mr Brown. Is that you?” and he was correct. The negative barriers vanished. Mr Brown became a contributor to meaningful life for others and gain purposeful living.

Professor Langer (1989) in her book, Mindfulness, commenced her book by giving an example of Action-Intelligence. The actions taken at a nursing home in Connecticut brought about “the powerful effects of what I came to call imidfulness.” Those in the experimental group were given “a choice of houseplants to care for and were asked to make a number of small decisions about their daily routines. … A year and a half later, not only were these people more cheerful, active and alert than a similar group who were not given these choices and responsibilities, but many more of them were still alive.” (Kennett, 2012).

Professional with care and compassion who go beyond the limitations of medicine will demonstrate effective coping strategies in improving behaviours. Effective coping strategies demonstrate Action Intelligence. Do not wait until the system changes because professionals only change systems by the actions they take. As Dr Adler wrote decades ago, “Trust only movement. Life happens at the level of events, not words.”

3 Later Professor Skinner (1945) focused on the only relevance of psychology and the helping professionals, being the effective change of behaviour that benefits individuals. Action Intelligence involves social competencies and coping strategies. Coping strategies involve
1. Information Seeking (reappraising the challenge upon which action, your response, may depend);
2. Direct Action (challenging self and/or the situation in meeting the challenge);
3. Inhibition of Action (giving attention for the wrong reason, resisting inappropriate response);
4. Cognitive Coping (action strategies that manipulates an individual’s attention and/or re-aranging the way events are apprehended and thus bringing about a reducton of the perceived challenge). OLazarus & Launier in Kennett (1992)

Social competencies are essential in all activites to support and encourage the wellness of our elders in caring residential facilities, their home. Adaptive behaviour is evident in effective coping strategies of professionals including, for example, imroved language skills (pronuciation) of many nursing aides, meaningful social activities, such as utilizing the strengths of the residents in weekly discussions, a weekly discussion on what residents might like, and encouraging regular social interaction with their family and friends, thus use of an ipad or small computer and the recording of the life history of the elder in their family. Elders must be encouraged to take the initiative, be responsible and contrute to their quality of life, refelcting what they were doing in the monhts prior to the security of 24/7 care.

Professor Kisely (2012) reported that community treatment orders may reduce one- and two-year mortality in the over 65 year olds. He acknowledges the value of increase contact with health services in the community. Increased social contact and new meaningful experiences are examples of the self-fulfuilling prophecy. Increase social contacts with a wide range of members of the community and give individual attention weekly with positive actions, guidance and focus on strengths and remarkable results follow. Rather than waiting to die elders are waiting for today and tomorrow’s new experiences.

- Social responsibility (ISO26000) is now a legislative requirements of all employers, employees and clients. Our governments have a direct responsibility to ensure implementaton. Professor Maria Barrios, Asian Institute of Management: Centre for Corporate Responsibility (Manila, Philippines, 2009) reported

- A world wide legal expectation to ensuring social responsibility in treating employees and clients.

- Governments and Corporate Institutions must demonstrate social responsibility taking accountability for the impact of decisions and actions on society and on the environment.

- To integrate ISO 26000 organizational leadership and core values and manifest its principles in work processes and transactions in relationships.

Millions of dollars are spent each year on research that confirms what is already known. Rather than the misnomer of Theory to Practice we need Practice (Action Intelligence funding) to change behaviours. As Jack Welch, former CEO, General Electric wrote,

“We don’t think ourselves into a new way of acting; we act ourselves into a new way of thinking”.

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Only action-intelligence research will change behaviours and bring about a new way of thinking. Action Intelligence (AQ©) is the only way those caring for our elders can collectively enjoy optimal experiences through adaptive behaviours.

Remember the 6 Plus 4 Steps for Action Intelligence (Kennett, 2112) commencing with

- **What we do?** Essentials of success
- **Which action do we select?** Coping Strategies
- **How we act?**

**Commitment Demonstrated by Strengths**

- **Why we act?** Optimal Achievement
- **When we act?** Optimal Timing
- **Where we act?** Recognition of environment and Specific Situation

Superior Action Intelligence (AQ©) implies that you act with positive intellect and empower others by the quality of actions. The AQ© paradigm is founded upon intelligent actions that establish a model of effective response patterns designed to promote a quality of life leading to happiness and harmony.

Confucius who wrote “I hear and I forget. I see and I remember. I do and I understand.”

The synergy of action-feeling-thinking is the foundation of Action Intelligence. Your actions are precious in the lives for whom you care. You determine their wellbeing and happiness. You are a model of excellence to imitate. Never forget your contribution.

AQ is the effectiveness of positive actions that identify and celebrate strengths, for example, in the elderly. New meaningful activities provide a purpose for living and can only be effective if time is taken to provide services with compassion and to identify personal interests and capacity to contribute. Depression or lethargy is prevalent in many aged care facilities. How staff act and the attention given determine improved meaning to life and maintain and restore past adaptive behaviours in the aged, who are always "at risk". A key component is the implementation of empowering others by positive actions. Human behaviour is the synergy of Action-Feeling-Thinking (AFT), a new paradigm applying practical knowledge to the theories of traditional curative approaches. Evidence based case studies are part of your experience, as you practice the P-CRAFT Principles of Behaviour. Prevention and intervention encompass the elderly, family and educational issues.

Rights only exist in our society when individuals act with responsibilities that bring respect, rewarded by supportive attention and recognition. Action Intelligence focuses on a new era of ignoring wrong responses and heavily rewarding right responses in bringing individuals into a meaningful quality of life, that involves new actions that empower through adaptive behaviours. New actions by the elderly will ensure new ways of feeling and thinking.

Effective responses patterns should be enjoyed by all. The enjoyment promotes progress. AQ is the way we learn effectively, the way we manage successfully and the empowerment of the way we lead.
References


Title

Understanding complex trauma and a Trauma-informed Approach to Care

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ABSTRACT

The majority of people presenting to mental health services have experienced complex trauma (secondary to child abuse, neglect, family/community violence or other adverse childhood event). This presentation highlights the importance of always considering the possibility of undisclosed or unaddressed childhood trauma underlying mental health presentations.

It challenges the medical model in categorising complex trauma and explore value in asking the question: “What happened to you?” at the core of many consumers’ presentations. Without addressing the core issues of their trauma these consumers will continue to ricochet around the system and have poor outcomes.

This presentation will highlight the need for a public health approach which incorporates both a trauma-informed to care and trauma specific services.

Keywords:
Recovery treatment
Complex trauma
Trauma-informed care
Understanding complex trauma and a Trauma-informed Approach to Care

Trauma seriously impacts mental and physical health, well-being and behaviour. It affects not only those who experience it but those with whom they have contact and the children they may go on to have. Individuals’ and society’s responses to trauma vary enormously but the majority of people who present to services with trauma-related problems have multiple unresolved traumas (complex trauma) which often leads to severe, diverse and persistent impacts.

Complex trauma can be caused by childhood abuse in all its forms as well as neglect and growing up with family violence or other adverse childhood event. Any form of violence experienced within the community – civil unrest, war trauma, genocide, cultural dislocation, sexual exploitation or re-traumatisation of victims later in life can also cause complex trauma.

In complex trauma the traumatic stressors are usually interpersonal – the trauma is premeditated, planned, and often repeated and prolonged and the impacts are cumulative. While interpersonal trauma can be one off events such as a physical or sexual assault, perpetrated by a stranger child abuse is more commonly perpetrated by adults on whom the child depends and trusts – family members or other adults in regular contact through school, church, sports or other community activities.

It’s important to differentiate single incident trauma often classified in terms of PTSD from complex trauma and deliver service responses accordingly as responses to complex trauma based on a diagnosis of PTSD alone are often seriously inadequate.

With child abuse the trauma is developmental. Research establishes the profound effects of extreme experiences not only on the developing brain in infancy but throughout the life cycle. It has provided the scientific basis for a diversity of behaviours and reactions to trauma, previously only observed.

Furthermore new research shows that with appropriate working through the trauma of even severe early experiences can be resolved. It suggests that changes to the brain occur in both directions—just as damaging experiences cause changes in the brain that are negative for subsequent functioning, new, different and positive experiences also change the brain in ways that are conducive to health. The challenge is to translate this research into effective practice.

Trauma is associated with an array of so called co-morbid problems including mental health challenges, poor physical health, substance abuse, eating disorders, relationship and self-esteem issues and contact with the criminal justice system. However I’d like to suggest that they are not co-morbid at all but rather an individual’s multitudinous responses to the lived experiences of trauma.

For over 100 years, clinicians have acknowledged the link between trauma, mental illness and psychosocial disadvantage. However, it was not until the feminist movement in the 1970s which exposed the consequences of interpersonal violence, and the work of clinicians
such as Bessel van de Kolk, Babette Rothchild, Judith Herman and others in the 80s & 90s that research findings provided strong evidence about the prevalence and impact of trauma.

A large percentage of those seeking help at a diversity of health and welfare settings have trauma histories. Of patients presenting to mental health services approximately 2/3 have a lived experience of some childhood abuse or neglect, or have grown up with family violence or dysfunction.

Despite the copious research base adult survivors of childhood trauma in Australia have been ignored in mental health policy reform and they have fallen through the cracks in service systems. The reasons for this are various. As a society we are confronted by trauma. Substantial stigma and taboo still exist around abuse, in general, and the legacy of abuse, in particular. There remains a collective denial about the scale of the issue and the often long-term complex needs of many survivors.

There remains a prevailing attitude that, as adults, people should be able to put their abusive childhoods behind them – on their own. Sometimes, the failure to acknowledge the issues extends to those who provide care.

There may be several reasons:

- a mental health system based on a ‘diagnose and treat’ approach to mental health care
- Clinical assessment which focusses on symptoms and signs and not underlying causes;
- A medicalised response for people impacted by trauma which is often not therapeutic;
- differing perspectives on the scientific validation of the lived experience of people presenting with trauma related symptoms;

Physical diseases fit neatly into diagnoses but the repercussions of trauma do not. This is evidence by the fact that many survivors frequently carry an array of diagnoses concurrently and over time. I was once my very own walking DSM IV. Anxiety disorder, depression, suicidality, Chronic PTSD, Dissociative Disorders. Thankfully my therapist didn’t pathologise me.

Given that recognition and integration of experienced trauma is generally considered fundamental to the recovery process this characterization makes little sense. The medical model works on the principle that something is wrong with a person. The substantive core issue of what happened to a person to impact them so profoundly is often relegated to ‘interest value’ only. With complex trauma something wrong was done to or happened to a person. I developed my mental health challenges because of what had happened to me, so called ‘normal’ reactions to extremely ‘abnormal’ circumstances. And as one of my medical colleagues at the time so delicately put it: “You’re not becoming one of those mental health patients are you?” Yet like all survivors I needed empathy, compassion and understanding, not judgement and labelling.
Anyone interacting with survivors needs to understand the effects traumatic life events have on the development of individuals. For me, finding a therapist who validated my experience, who bore witness to what had happened to me, who I learnt to trust, who gave me unconditional support, who listened empathically and who could contain my angst and help me feel and be safe, was crucial to my recovery.

Many adults who have experienced adverse childhood experiences have adopted extreme coping strategies as an attempt to manage overwhelming traumatic stress. These often persist into adult life and many, such as smoking, substance abuse, physical inactivity, overeating and high risk sexual behaviours become risk factors for later health problems.

Other coping strategies include suicidality, self-harming behaviours such as cutting and burning, dissociation, and re-enactments such as abusive relationships. Whilst challenging, in the context of trauma these behaviours make perfect sense.

By way of example let’s talk briefly about the diagnosis of Borderline Personality Disorder. This diagnosis is pathologising. It carries enormous stigma and consumers are often labelled as ‘borderlines’. This depersonalizes them further as they become their condition, this label becoming their identity, a less than human with a fundamentally flawed personality.

The diagnosis implies hopelessness, manipulation and resistance to treatment and consumers internalize these expectations, and they become a self-fulfilling prophecy. No one is denying the challenges of caring for someone who idealises you one minute and denigrates you the next, who makes repeated suicide attempts and is self-harming.

However if the behaviours which characterize BPD are understood in terms of traumatic stress, disrupted attachment, personal invalidation and adaptive coping strategies it is easier to understand and empathise with challenging behaviours and reactions. That person is communicating the intensity of the pain at their core, as best they can. Over time listening to them and you may be the very first person in their life who has, and listening to their behaviour in the context of what happened to them, will help them to trust you and build a relationship which is crucial for their recovery.

Abuse in childhood often sets up lifetime patterns of fear and mistrust. It affects a person’s identity, self esteem and sense of self worth, their relationships not only with themselves but with others and with the world, the ability to regulate emotions, to self-soothe and self-care and to manage stress. Adult survivors often additionally struggle with somatic symptoms and chronic feelings of hopelessness.

When a child is abused the child takes on an inappropriate sense of shame and self-blame and these feelings often continue into adult life. Even though survivors may want to talk about their feelings, their own shame as well as fear of how others will respond can stop them from doing so. Child abuse is about being and feeling unsafe and survivors try to protect themselves from being hurt again. Hence survivors will tend to withdraw, isolate themselves and not seek help and engage in/or sustain treatment.
Survivors can learn how to trust, feel safe, relate to others and manage their emotions and many do go on to live healthy and productive lives but to do so survivors need support, empathy, understanding and respect. Our current systems of care often ignore the underlying trauma at the core of survivors’ issues, not viewing it as pivotal, and often invalidate, negate or dismiss it. Doing so comes at a huge cost, not just to individuals but to families and communities. ASCA witnesses that cost every day in its work.

Every day ASCA receives calls from child abuse survivors who cannot find or afford the care and support they need. They have experienced a health care professional who has been disempowering, re-victimising or otherwise unhelpful; a GP who was uninformed, who didn’t inquire about trauma despite symptoms which were highly suggestive. A worker who didn’t know how to respond to a disclosure, a counsellor, psychologist or psychiatrist they felt had minimized or dismissed their feelings and experiences rather than listening empathically and validating them.

It is staggering how often survivors are told things like “It happened such a long-time ago; there’s no value in talking about it. What does it matter? Stop whingeing about it.” Some workers believe that talking about past traumas is irrelevant and self-pitying or imply that the trauma was the person’s fault, that he/she is carrying on about nothing, making things up, exaggerating, or has a personality disorder.

While some survivors of child abuse show remarkable resilience many are disadvantaged, not only by their trauma but also by the accompanying socio-economic disadvantage. Meeting the needs of adult survivors can be challenging for all of the reasons I’ve outlined (the deep feelings of insecurity, sensitivity of criticism, low self-esteem, difficulties with trust and interpersonal relationships, substance abuse, self-harming, suicidal and risk-taking behaviours with which many survivors struggle).

Recognising the adaptive function of “symptoms” helps reduce guilt and shame, increases self-esteem, and provides a pathway for developing new skills and better adaptations. Validating resilience is important even when past adaptations and ways of coping are causing problems in the present. Survivors need to feel understood and have their experiences heard and validated.

Survivors generally also benefit from making connections between their past experiences and their current situation as part of an integrated recovery journey, making sense of their past, enabling them to ultimately view their abuse as part of their history.

However none of this can occur in isolation. Relationships are crucial to the process of recovery but the nature of those relationships is vital. As the relationships which caused the original trauma were disempowering and controlling, relationships of care and support must be safe, consistent and constructive, non-violent, non-blaming and non-shaming, and feature persuasion and not coercion, ideas and not force, and mutuality rather than authoritarian control.

Establishing firm and clear boundaries as well as predictable environments, and well defined roles allow survivors to feel empowered and re-build a sense of self-efficacy and personal control - factors which are essential to recovering from the overwhelming fear and
helplessness that is the legacy of victimisation. Approaches should be collaborative and mutually respectful with the survivor setting the pace. This allows survivors to build on their strengths, and resiliency, and to further develop their coping skills while embracing hope and working towards a positive future.

The high prevalence of complex trauma is frequently unrecognized and subsumed within other diagnoses, where presenting problems are considered in isolation from the unacknowledged underlying trauma. Complex trauma is often compounded when unrecognized. Trauma survivors with complex needs often experience a range of mental and physical health, substance abuse problems and other life burdens. Many trauma survivors have not connected their current problems and behaviours with their past traumatic experiences and nor have their health workers, a reflection of the prior lack of adequate training around trauma. A holistic approach to care and support is needed and yet to date care is often fragmented with little to no co-ordination between services along with poor referral and follow-up pathways.

Trauma survivors characteristically seek help from a diversity of public, private and community services over a long period of time. Services tend to focus on crisis and risk management which deliver short term rather than the longer-term interventions needed for sustained recovery. In cities and towns it is hard to access expert long term and affordable counselling/therapy and/or skilled groups and workshops. In rural and regional areas services are virtually non-existent. Mainstream services are overstretched and cannot adequately address their needs. There are exceptions; some specialist services are sensitive to survivors’ needs but they are few and far between. Often they depend on an individual rather than a service culture and when the individual leaves, so does the possibility for trauma informed care and sustained recovery.

Services often mirror the power and control experienced in past abusive relationships. Current systems commonly pathologise survivors and their presentations and a lack of awareness around potential triggers leaves survivors open to re-traumatisation. Trauma survivors often experience services as unsafe, disempowering and/or invalidating. Often times they do not know where to turn and effectively give up. Currently the majority of survivors cannot access and/or afford to sustain the holistic support they need to make sense of their histories and work towards recovery.

So what do we need to see? Let’s talk about a trauma informed approach to care.

“Trauma-Informed Care and Practice is a strengths-based framework grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes physical, psychological, and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment.”

TIC is grounded in a thorough understanding of the neurological, biological, psychological and social effects of trauma and violence and the prevalence of these experiences in persons who receive services. Trauma informed care involves the provision of services that
do no harm – e.g., that do not re-traumatise or blame victims for their efforts to manage their traumatic reactions.

**Trauma Informed Care & Practice** involves changing assumptions about how we organise and provide services and creates organisational cultures that are personal, holistic, creative, open, and therapeutic. Service providers move from a caretaker to a collaborator role.

A rapidly expanding research base attests to the substantial *public health* costs of unresolved trauma. Recognition, treatment and funding of trauma are a *national priority*. We need to see a public health approach which incorporates both trauma-informed (recognition of trauma in clients and establishment of systems that are aware, responsive and do not exacerbate it) and trauma specific services (specialised capacity to address trauma per se). And an understanding around complex trauma as distinct from single incident trauma and programs and services which meet the needs of those with complex needs as a consequence of a lived experience of compounded trauma.

ASCA has recently completed a set of Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery. These Guidelines distil the last 20 years of national and international research and have established an evidence base around responsiveness to trauma, with pathways to practice and recovery. These Guidelines support the work, in which ASCA is involved, on the Trauma Informed Care and Practice Advisory Working Group, under the leadership of MHCC.

The AWG is seeking to drive a national agenda around trauma informed care and practice. Together these initiatives, once adopted will spearhead the changes needed for mental health policy and practice reform around trauma.

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2 Babette Rothchild. 2000. The Body Remembers: The Psychophysiology of Trauma and Trauma Treatment

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ABSTRACT

Academics of the Nursing and Rural Health Unit at the University of South Australia at Whyalla in partnership with staff of Country Health SA are delivering a Mental Health course for a group of on-campus nursing students. The course aims to develop the knowledge, skills and attitudes to enable students to understand mental health and common mental health issues. The impact of this collaborative initiative will be determined through a twelve-item electronic-based questionnaire. The questionnaire will examine students’ experience with the learning approach, clinician-driven activities, best aspects of the course, impact on learning, and areas for improving future offerings. The early findings of the evaluation will be reported during the conference presentation.

Keywords: mental health educational preparation, clinicians and practitioners as teachers

Introduction

This year, a new course is being introduced by the University of South Australia (UniSA) following the rolling out of the revised nursing curriculum. The new course is Mental Health, a 4.5 unit course delivered on and off campus for Bachelor of Nursing first-year students. The aims of the course are to develop the knowledge, skills and attitudes to enable students to understand mental health and common mental health issues. The course content includes: mental health and wellness across the lifespan, cultural and social construction of mental illness, mental state assessment, therapeutic communication skills, schizophrenia, psychosis, depression, anxiety disorder, bipolar affective disorder, personality disorders, self-harming behaviours, suicide, de-escalation of anger, psychopharmacological and psychosocial interventions, recovery, evidence-based practice, safety and quality, law and ethics, Mental Health Act, Guardianship and Administration Act (UniSA, 2012). The course assessments include: an assignment, a mental state assessment and a case study. The graduate qualities being developed in this course include, among others, sufficient body of knowledge, problem solving and ethical action and social responsibility.

Academic staff of the Nursing and Rural Health Unit at UniSA’s Centre for Regional Engagement partnered with staff of Country Health SA in order to deliver the course at the regional campus. This partnership initiative was undertaken not only to meet the objectives of the course, but to value-add by promoting good mental health amongst students, exposing students to mental health practice in rural and regional areas, providing opportunities for students to work closely with mental health nurses, increasing interest in mental health nursing, and contributing to the positive learning and teaching experiences of students, staff and community members. The teaching arrangement featured the clinician, practitioner, academics, invited experts and community members actively involved in the structured tutorials which run for three hours a week for nine weeks during a study period. This partnership between the university and industry in teaching mental health is a departure from our traditional university formats.
The purpose of this paper is to describe the partnership model implemented by the academics, clinician and practitioner. It will also discuss students’ and staff’s early reactions to some aspects of the course, specifically in relation to this collaborative teaching approach. The paper first introduces the pedagogy or educational framework underpinning the teaching of the course, which is inquiry-based learning, followed by a description of the partnership, the structured tutorial activity and the instrument we plan to use to evaluate the initiative. The early reactions of students, university staff, clinician and practitioners are highlighted. Note that early reactions are reported because the complete and final evaluation of the partnership approach will be conducted at the end of the course, which concludes after this conference. The initial achievements of the initiative conclude the paper.

Background

A decision was made to use inquiry-based learning (IBL) as a framework for teaching nursing courses including the Mental Health course that is the focus of this paper. In IBL, learning is organised around the individual rather than the content (Duffy & Cunningham, 2001). The concept of this approach to learning and teaching is one where the students learn problem-solving skills and informal reasoning, as well as constantly seeking relevance and connections (Duffy & Cunningham, 2001; Stripling, 2003). IBL falls under the constructivist approach characterised by collaboration, active engagement and personal relevance, amongst others (Savery & Duffy, 1996).

IBL is premised on the belief that education begins with the curiosity of the learner (Savery, 2006). Beginning with a question, the process is followed by an investigation, then creation of new knowledge as information is gathered and understood, discussion of discoveries, and, finally, a reflection on the new knowledge. The Stripling model of inquiry illustrates the IBL approach as a series of steps, namely, connecting to self, wondering and questioning, evaluating information, constructing new understandings, expressing new understandings and reflecting on one’s own learning (Stripling, 2003).

This approach encourages students to bring their knowledge and experience to a situation and explore comprehensively problems, issues, and concepts in order for each area to be adequately addressed. There is a shift of focus from teacher to students; students are primarily responsible for their learning (Bebb & Pittam, 2004). Another feature of IBL is its emphasis on active engagement in the group process (Cleverly, 2003a). As such, it fosters student–student and student–staff interactions.

The students go through the various IBL phases (Cleverly, 2003a). Brainstorming of the scenario, determining what is known and not known, and eliciting broad insights happen during the exploring phase. Presenting new information to the group, applying information to the scenario, and exploring all possible alternatives occur during the reviewing phase, while synthesising ideas, developing an action plan, and constructing new understanding are manifested in the consolidating stage. The reflecting phase encompasses looking back, examining individual and group learning, and identifying further learning needed.

Moreover, there has been ongoing concern in nursing about the gap between theory and practice, education and service, and, more recently, practice and policy concerns over the gap between evidence-based practice and the realities of community practice. Collaboration between academics and industry staff in the provision of undergraduate education is considered to be a strategy for overcoming some of these problems (Gassner, Wotton, Clare, Hofmeyer & Buckman, 1999). The same authors determined that collaborative relationships facilitate the successful development and implementation of reality-based learning for students.

In the field of business, a partnership refers to two or more individuals embarking on a project for mutual benefit. In education, organisations and individuals instigate
arrangements where they agree to cooperate to meet goals and promote interests. However for partnerships to work, understanding of goals, expectations and characteristics associated with partnership success are paramount. The primary characteristics of partnership success are commitment, coordination, and trust. In addition, other attributes include excellent communication, active participation, effective conflict resolution technique and joint problem solving (Mohr & Spekman, 1994).

With clear roles and responsibilities of each partner in mind, the staff involved clarified how each might mutually benefit from the relationship. Specifically from the academics’ perspective, partnering with a knowledge broker, senior mental health clinician and a mental health practitioner can potentially yield advantages, such as being able to hear from on-the-ground clinical experience, providing opportunities to learn about mental health issues specifically relevant for regional and rural areas, bringing a diversity of skills and experience in mental health, and communicating their passion in this specialised area. From the clinician’s and practitioner’s perspective, there is opportunity to reduce the stigma attached to mental illness, increase students’ interest in mental health nursing, increase participation in mental health clinical placements, and increase student capacity to assess and care for patients with mental conditions, as well as care for their own mental health.

**Inquiry-based learning structured tutorial**

Each week, students are provided with course topics they need to work through before presenting to class. They are assigned readings and undertake various activities which could be individual or group activities. On the day of the tutorial class, they come together and share their findings. Together, they construct new understandings of the topic. They discuss their understanding and their work on campus with the facilitators and peers.

Some real-life case scenarios are provided. A scenario typically reports on a client in the hospital or community setting with mental illness. The case scenario is complete with family history, signs and symptoms, investigations, treatments and interventions, and students attempt to make sense of the assessments conducted and understand the illness process in order to identify the client’s nursing needs. They consider all human dimensions that might be impacted by the mental illness and determined appropriate nursing actions.

Prior to the day’s tutorial, students read the scenario, and connect with it by bringing previous knowledge and experience to the group discussion. They gain some background and relate the scenario to personal experiences. They ask themselves, “What do I know about this topic?” Based on what they know about the case, students then ask, “What more should I know about this topic?” They develop questions and determine what pertinent knowledge they should be seeking. They conduct research, undertake a review of literature, interview experts, and review the information they have gathered. They utilise online and print-based materials to gather information. They apply this new information to the scenario, synthesise and draw conclusions. Each group member expresses the new knowledge and insight and applies this to the scenario. They then reflect on their own learning and formulate new questions as needed. They ask, “What new knowledge have we gained which we can apply in future practice?”

In the delivery of the tutorials, various teaching methods are used. In addition to case scenarios, some other approaches include: the ‘university street café’ style, open discussions which are more like rich conversations and dialogue, where experts talk and share service experience, community members teach and share experiences, role play, storytelling, and technology-assisted learning in the form of YouTube, online readings, blogs and activities. Tutorials conclude following reflections of the learning that has taken place and debriefing where students and staff clarify what has worked and what has not worked.
The tutors for the IBL structured tutorials act as guide or mentor. They assume facilitator roles during these tutorials, assisting students to be actively involved in the group process. They guide students in using a variety of questioning strategies, encourage them to develop clinical reasoning skills, support students to connect with past experiences, and highlight the need to be self-directed. They enhance motivation by providing a cooperative and collaborative atmosphere (Cleverly, 2003b).

Method

The impact of this clinician/practitioner and academic partnership in delivering a mental health course will be determined through an online questionnaire (using UniSA’s TellUs2 application) completed by students at the end of the course. Aspects of the course to be examined include: experience with the learning approach, clinician-driven activities, best aspects of the course; impact on learning, and areas for improvement. The students will be invited to participate in the evaluation, emphasising that participation is voluntary and that information they will provide will be used only for research purposes. Anonymity of individuals participating in the study will be maintained.

The survey instrument consists of 12 statements where the students respond using a Likert scale from 1 to 5, 1 meaning ‘strongly disagree’, 5 meaning ‘strongly agree’. The students will be asked about their satisfaction with the learning experience, adequacy of learning opportunities, understanding of mental health (history, nature, scope), understanding of common mental disorders, nursing interventions, role of mental health nurses, confidence gained in performing mental state assessment, attitude towards mental illness, value placed on mental health nursing, the best thing/s about the course, something that could be improved in future offerings, and additional comments. The qualitative data gathered will be collated, tabulated and analysed.

As the course is on-going, early reactions of the course offering were determined by asking students, “What was it like to participate in the mental health course delivered by academics in partnership with mental health clinician and practitioner?” The staff facilitating the course were asked, “What was it like to deliver the course to first-year nursing students utilising the partnership approach?"

Early findings and discussion

The significance of introducing learning strategies that not only present knowledge as traditional approaches do, but engage students meaningfully and encourage greater interaction, motivate the staff to continue developing strategies that boost learning, enhance interactivity, and achieve academic rigour. The IBL framework has features of teaching situations that provide direct and adjunct instruction, facilitate skills for learning, as well as extend social skills, and widen the students’ views and understanding. A university academic reported:

I really like the IBL structured tutorials. There is greater depth in learning, more interaction and exchange of ideas. However, its impact and effectiveness is further enhanced with the involvement of experts in the field.

Initial reactions of the partnership approach to teaching nursing students mental health reveal that the initiative has the potential to enhance the quality of the students’ learning experience for a number of reasons. Firstly, the partnership approach promotes the transfer of expertise across students and academic partners. The transfer of knowledge and expertise translates to local capacity building. A mental health academic and knowledge broker support this belief, stating that:

This is an exciting opportunity to build relationships and working relationships between industry, learning and academia, to assist students, nursing in this case transfer knowledge into practice. … most important for capacity building.
Secondly, the authentic partnership approach enhances learning because it emanates from experts’ practical experiences which can potentially narrow the gap between theory and practice. Students are afforded the opportunity to gain an understanding of the current workplace environment, which will better prepare them for future practice. They gain insights into the many dimensions of practice and possible alternatives in caring for mentally ill clients as they observe and discover how clinicians and practitioners think and behave.

Consider some of the students’ comments about the clinician-driven tutorials:

- *The experience is extremely good and enjoyable. I learn a lot. It affords me a ‘realistic’ window of what goes on in a mental health service.* (Nursing student 1)

- *Very enlightening learning different stories. It broadens my view. I am able to witness how mental health experts think, rationalise, behave and solve problems.* (Nursing student 2)

Thirdly, the approach achieves a high level of interaction and engagement for the students. The students are encouraged to read and engage with the course material and interact with clinicians and practitioners who affirm and challenge their beliefs and understanding and who provide them with different perspectives. A case in point is the stigma attached to mental illness and the complexity of caring for patients with mental conditions. In our partnership arrangement, knowledge is contextualised, interpreted and made more meaningful for students. Also, students feel more supported in their study. There are opportunities to develop and practise various skills, such as caring for one’s own mental health, mental health assessment, communication, team work, problem-solving and behaviour management.

The following remarks illustrate further the benefits of the partnership approach:

- *There is more support in the study, more interaction, more insight gained.* (Nursing student 3)

- *Students will learn the recovery journey and the lived experience, inspiring them and providing rich tutorials that would be invaluable to them as they prepare to embark on their careers.* (Mental Health Practitioner)

- *An excellent opportunity to teach ‘fresh’ students to look after their own mental health.* (Mental Health Academic and Knowledge Broker)

Fourthly, the quality of learning is enhanced because the ideal and appropriate professional values and attitudes of clinicians and practitioners are communicated. The clinicians and practitioners serve not only as teachers but as role models as well. Their educational involvement with students is a strategy by which ethical action and social responsibility may be inculcated. There is also the opportunity to inspire the students to pursue this area of specialty as the staff share their passion and motivation in their work.

The excerpts below demonstrate these sentiments:

- *This is a great opportunity to showcase Mental Health Nursing as a career option and to enhance people’s mental health literacy.* (Senior Mental Health Clinician)

- *Students will come to realise the significance of this field of study through the lens of experts and experience vicariously the tremendous satisfaction of helping people with complex mental health issues.* (University Academic)

- *We hope to encourage rural-based student nurses to consider a career in mental health, which will also improve recruitment and retention of health professionals in rural communities.* (Mental Health Academic and Knowledge Broker)
However, while one student likes the inputs of the mental health workers, she was confused with the conduct of tutorials. She explains, "I'm not used to having clinicians conducting tutes." This signifies the need to prepare to students when trying out innovations.

The overall desirable learning outcomes achieved so far are attributed to the authentic partnership created, and this partnership must be sustained. The aspects of the partnership that are helpful include: clear goals, flexibility in pursuing the goals, cohesive strategies and actions, mutual respect, recognition of capacities, active and equal participation, mutual trust and benefit, and meeting of needs and expectations. Similar to Jones and Wells’ 2007 description of what community engagement is, finding the "win-win" possibility and sharing in the planning and implementing are crucial for successful partnerships.

Conclusion
This partnership between the university and industry in teaching mental health is a radical departure from traditional university formats. Early findings from a class survey show an overall satisfaction with the partnership approach in teaching, highlighting the enriched discussions, added value and positive learning experiences for first-year nursing students.

This is a start to an ongoing industry and academic partnership which will provide the basis for future collaboration opportunities in education, research and clinical practice in a rural setting.

References


A randomized non-inferiority trial of psychosocial treatment interventions: a comparison of PETA, CBT and case management for patients with severe mental illness or disorder (SMI) in a community mental health service.

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**ABSTRACT**

Severe mental illness (SMI) refers to a group of relatively low prevalence but high severity disorders such as schizophrenia, bipolar disorder and severe personality disorder, all characterized by substantial impairment of functioning and high need for treatment and monitoring. SMI is often associated with high levels of psychological distress and increased levels of cognitive impairment; people with such disorders make up most of the patient group of public mental health services. Those patients diagnosed with SMIs such as schizophrenia and schizoaffective disorder frequently experience depression, anxiety, reduced self esteem and low self-efficacy as well as primary symptoms of psychosis. These may be conceptualized either as symptoms of the illness itself or as symptoms resulting from adjustment to the illness and associated impairment. Despite the high prevalence of these kinds of psychological problems among people with SMI, there are few evidence-based psychosocial interventions designed to assist in their management. There has been some evaluation of cognitive behavioural (CBT) interventions for non-psychotic depression and anxiety experienced by people with SMI but the findings have been mixed, and it is possible that these interventions are not sufficiently attuned to the specific needs and cognitive capacities of people with SMI. The aim of this research is to evaluate a previously untested psychosocial intervention (PETA) that operationalizes the stress-vulnerability-coping model of mental illness and was specifically developed for people with SMI. The proposed evaluation takes the form of a 3 armed randomized controlled trial whereby participants are assigned either to PETA plus treatment as usual (TAU), to a psychosocial intervention with an established if modest evidence base with this population (CBT plus TAU), or to TAU only. TAU typically consists of medication plus case management. Outcomes with respect to self-esteem, self efficacy, relationship satisfaction and clinical symptoms will
be compared for the three groups. The study will use a repeated measures design with measures administered pre-intervention, post-intervention and at 3 month follow-up.

**Keywords:** Psychosocial treatment, Severe Mental Illnesses, adults.

**PAPER**

Rationale and Background Information - Introduction

There exists relatively little research into psychological interventions for serious mental illnesses, with only 23% of psychological research focused on this area of mental health (Martin, Garske, & Davis, 2000 and Bieling, McCabe, & Antony, 2006).

It has been established that cognitive deficits are common in psychiatric disorders and have also been shown to be present prior to the onset of such disorders as bipolar disorder and schizophrenia (Atre-Vaidy et al., 1998; Brewer et al., 2006; Elvevag & Goldberg, 2000; Robinson & Ferrier, 2006; Woodberry et al., 2011).

Debate continues on whether cognitive deficits are a consequence of mental illness or related to other factors associated with the illness, such as substance use or medication effects (Dickerson et al., 2004; Green, Kern, Braff & Mintz, 2000; Martinez-Aran et al., 2004).

Some authors and researchers have suggested that cognitive ability may serve as a “rate-limiting” factor; i.e. an individual, identifiable, altering and restrictive factor that influences engagement in the success of medication compliance, specific therapies, or psychosocial interventions (Bell & Bryson, 2001; Jeste et al., 2003; Kurtz, Seltzer, Fujimoto, Shagan, & Wexler, 2009; McGurk, Mueser, Harvey, LaPuglia, & Marder, 2003; Smith, Hull, Romanelli, Fertuck, & Weiss, 1999; Wiedle, 1999).

It has also been found that compromised neurodevelopment and early cognitive dysfunction have a direct correlation to and can result in the formation of maladaptive coping mechanisms or schema, which may influence psychiatric symptom expression (Allott et al., 2011). Hence, previous cognitive dysfunction and poor or limited coping mechanisms are also interconnected and impact upon how an individual experiences symptoms of SMI. According to Allott (2011, p.16): “cognitive dysfunction may contribute to poor functional outcomes to an equal or greater degree than psychiatric symptomatology”.

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In recognition of the prevalence of cognitive deficits among people with SMI, the PETA (The Psychological Egg Treatment Approach) therapeutic model reduces demand on participants to make ‘psychological connections’. As therapy components are concrete, the PETA Model effectively targets both the positive and negative symptoms of SMI.

Table 1 below sets out the therapeutic assumptions of CBT and PETA, highlighting the benefits of PETA therapy for patients with SMI where cognitive abilities (typical trauma and memory considerations) and general global functioning (ability to plan or complete tasks as per prior established capacity) are reduced, restricted or disengaged as a result of SMI.

The assumptions as they pertain to CBT are sourced from:

Safran, J. D., & Segal, Z. V. (1990),

Padesky, C., & Greenberger, D. (1995) and

Bieling, P. J., McCabe, R. E., & Antony, M. M. (2006). The assumptions of PETA are based on

Table 1

<table>
<thead>
<tr>
<th>Assumptions of CBT Therapy</th>
<th>Assumptions of PETA Therapy</th>
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<tbody>
<tr>
<td>Ability of patient to make ‘psychological connections’. Requires patient to have psychological i) ability and ii) flexibility to make and comprehend psychological connections.</td>
<td>Patient is not required to make ‘psychological connections’, as areas defined in assessment and therapy are ‘discrete’, ‘concrete’ and ‘transparent’. Refer to 5 areas of investigation – Table 2.</td>
</tr>
<tr>
<td>Requires patient to possess a stable ‘Sense of Self’ and level of ‘Self Insight’.</td>
<td>Patients are not required to possess self insight and emotional regulation skills – i.e. Sense of Self / Identity. The PETA Model assumes emotional regulation can be learnt and Sense of Self and Insight can be developed.</td>
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<td>Assumed level of patient exposure to normative life experience and obtaining developmental milestones; (i.e. assumed high level of patient interpersonal skill and psychological, emotional, social and behavioural functioning).</td>
<td>Acceptance that all patients may not experience appropriate exposure to developmental milestones and in turn experience differing levels of trauma. Patients may not experience relationships that impact positively on interpersonal skills and psychological, emotional, social and behavioural functioning.</td>
</tr>
<tr>
<td>Adequate cognitive and global functioning. Therapy requires Moderate to High cognitive ability (i.e. moderate Attention, Comprehension, Memory capacity) and interpersonal functioning.</td>
<td>Restricted, limited, reduced cognitive and global functioning. Therapy designed for Moderate to Low cognitive ability (i.e. reasonable to low Attention, Comprehension, Memory capacity) and interpersonal functioning.</td>
</tr>
<tr>
<td>Capacity to understand reciprocal interactions and ‘causality’ links between Self (i.e. connections and interactions of thought, emotional, behavioural, psychological and physiological responses) and the environment.</td>
<td>Emphasis is on client defined meaning.</td>
</tr>
</tbody>
</table>
Refer to Appendix A (PETA) for detailed therapy assumptions, propositions and components.

**Current Research in the Field and Significance of Research**

While numerous studies (Morrison, 2001; Morrison et al., 2004 and Bieling et al., 2006) have demonstrated that CBT is an effective group intervention for the treatment of mild and moderate depression, CBT has limited effectiveness with the population of patients with SMI (Miller et al., 2000, 2003; Habey et al., 2005). Indeed, while promising for moderate or mild disorders, CBT does not appear to deliver the kinds of reliable and substantial treatment gains that are evidenced in the treatment of mild to moderate anxiety and non psychotic depression (Lynch, Laws & McKenna, 2010).

Individual and Group CBT has been an empirically validated form of psychotherapy that has been shown to be “effective in over 350 outcome studies for a myriad of psychiatric disorders, ranging from depression to anxiety disorders, and more recently to personality and psychotic disorders” (Beck & Weishaar, 2000, in Bieling, et al., 2006, p 3). Miller and colleagues (2001) found that when CBT was added to routine inpatient treatment for depression, 54% of patients remained well at one year follow up, compared with only 18% of those offered ‘usual care’. However, while this research supports the value of CBT for treatment of high prevalence disorders, the effectiveness of CBT for people with SMI is less clear.

Current research into CBT effectiveness for SMI suggests that CBT is not effective in reducing symptoms in schizophrenia or in preventing relapse. In a meta-analytic review of well controlled trials of CBT for SMI, Lynch et al. (2010) found just a small effect size in reducing symptoms in major depression and no benefit in reducing relapse for schizophrenia or bipolar disorder.

PETA was specifically designed for patients with SMI, accommodating for cognitive deficits relating to the illness and or associated trauma. The model supports and structures the development of the self, social and functional domains that are considered imperative to
good self esteem, self efficacy and social interaction. Assessment and therapy components address: exposure to life stressors, coping style, interpersonal variables such as communication style, love style, emotional regulation, and other variables such as motivation, goal setting and time management. The model provides the framework, scope and tools to treat ‘negative’ symptoms which no other therapy has effectively addressed. It also allows for evaluation of individuals with good mental health. An assessment of physical health and its impact on the patient is also addressed. Table 2 identifies PETA’s areas of assessment and therapy.

Table 2

PETA MODEL OF FIVE EGGS – AREAS OF ASSESSMENT AND THERAPY

- E1 – Exposure to Life Stressors;
- E2 – Coping Style (and Decision Making and Problem Solving);
- E3 - Interpersonal Variables (Romantic Satisfaction (or Patient identified relationship as Significant), Love Styles and Communication Styles and Emotional Regulation;
- E4 – Temperament and Other Personality Variables (Motivation, Goal Setting and Time Management; and
- E5 - Physiology and General Well Being (in *Cracking Eggs to a Brighter Future*, te Braak, 2008).

PETA utilizes the following Assessment / Inventory Measures

- Life Stress Index (Monroe et al., 1992).
- General Well Being Schedule (GWB) (Dupuy et al., 1984, pp. 170-183);
- A Coping Inventory for Stressful Situations (Endler & Parker, 1990);
- Romantic Satisfaction (Burns, 1999).
- Communication Categories (te Braak, 2008, pp. 62-64);
- Love Styles (Lee, 1988) (te Braak, 2008, pp. 10-11);

Refer to Appendix A for more detailed information on PETA.

A recent study by Economou, Palli, Peppou, and Madianos, (2011) supports the application of evidence-based integrative strategies to routine services as long as they are provided in a timely manner (refer to “TAU plus CBT” Structured Therapy Groups in Groups Section). The proposed
research will provide valuable information on the efficacy of PETA as a purpose designed psychosocial treatment approach for people with SMI receiving treatment in community mental health services. The results may reveal that PETA is a more effective treatment than CBT for SMI, with more significant reductions in clinical symptoms and greater increases in levels of self esteem, self efficacy and relationship satisfaction. It is hoped that greater improvements will also be evident in patients’ general global functioning, rendering PETA an effective psychosocial treatment for patients with SMI.
Targeted Community Care –
Working in Partnership to Support Respite and Recovery

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ABSTRACT
The aim of this paper is to educate on the importance of carer inclusion and the flexibility and rewards of respite. We want to promote national respite initiatives whilst re-defining “respite”, sharing good news stories of recovery, successful partnerships, our unique approach and available funding. This paper is designed to share information on the implementation and strategies of our programs. It will include information on context and background of Commonwealth Carelink and Respite Centres and the Mental Health Respite Program, profile of carers and recipients, statistical analysis of the client population, developments and initiatives, program model, strategies for successful partnerships, customer feedback analysis, good news stories and positive program outcomes.

BACKGROUND
There are fifty-four Commonwealth Respite and Carelink Centres across Australia hosting a range of Commonwealth and State-funded programs for community access. The national network of Commonwealth Respite and Carelink Centres is an information source providing free and confidential information regarding community aged care, disability, mental health and other support services available locally, interstate or anywhere within Australia. The Commonwealth Respite and Carelink Centres also assist carers with respite by providing appropriate short-term or crisis services for their care recipients.

The Mental Health Respite Program (MHRP) as funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) is one of the specialist respite programs offered and operates within the Targeted Community Care guidelines. The program aims to assist individuals with severe mental illness, their families, carers and children at risk of developing mental illness through the provision of accessible and responsive community support services. This provides opportunities for recovery to overcome social isolation, support to families and carers as well as promoting early intervention for children and young people at risk of mental illness.

The Council of Australian Governments has signed a new National Partnership Agreement supporting the National Mental Health Reform. The agreement provides $200 million in Commonwealth funding, alongside investments by the States and Territories, to improve outcomes for people with severe and persistent mental illness. (http://www.health.gov.au/internet/ministers/publishing.nsf). The Australian Government in particular has committed more than $774 million for the Mental Health Respite Program over
the next 4 years where “funding for the Program will be ongoing.” (Australian Department of Families, Housing, Community Services and Indigenous affairs (2011))

TARGET GROUP

The target groups for priority access to this program are those who are most disadvantaged within the community. This population includes younger carers, older carers, Indigenous Australians and people from culturally and linguistically diverse backgrounds.

The Commonwealth Carelink and Respite Centre MHRP in the North Metropolitan region of Perth has approximately 780 carers registered on our database, providing support to an individual with a mental illness, severe intellectual disability or autism. The largest proportions of program users are mental health carers and their recipients, which accounts for 45% of carers within our program. For the remainder of the article we will be concentrating on this client group specifically.

IDENTIFYING CARERS

“Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged. There are currently over 2.6 million unpaid family carers in Australia, more than 770,000 of whom are primary carers - the people who provide the most care” ABS (2009) Survey of Disability, Ageing and Carers.

The Commonwealth Carelink and Respite Centre MHRP identify carers as those who assist with three areas of core activity: mobility, communication and self care. Mobility involves the provision of assistance with transport such as taking the person to appointments or accompanying them on public transportation. Communication includes assistance with decision making, financial or emotional support, paperwork or helping someone to seek information about support services they are eligible for. Self Care refers to assistance with medication management, nutrition, accommodation, personal hygiene and supporting physical health, safety and wellbeing of the person they care for.

CARER INCLUSION

The Commonwealth Carelink and Respite Centre MHRP recognises the importance of carer inclusion as it leads to better outcomes including focusing on communicating effectively and sharing information with the carer to ensure continuity of care. The team values and recognises the essential role that carers play in supporting the care recipient in their day to day activities.

The Carers Recognition Act (2004) provides a clear direction on how carers are to be treated and involved with all aspects of care. The Commonwealth Carelink and Respite Centre MHRP undertakes all practicable measures to ensure that we comply with the Carers Recognition Act whereby carers needs and views are incorporated during all aspects of the assessment, planning, delivery and review of those services. Where consumers refuse to consent to the sharing of information, general information about mental illness can still be given to carers without breaching confidentiality, thereby empowering carer with having the knowledge.

The Commonwealth Carelink and Respite Centre MHRP have key working partnerships with consumer, carer, clinicians and service providers to strive for better outcomes for all. The team works closely with Mental Health Service Providers to increase the support services
linked to the client and family, which optimises recovery outcomes and decreases pressure for ongoing intensive mental health services.

THE CARERS WE SUPPORT

At the Commonwealth Respite and Carelink Centre, our client is the carer. The team supports the carer in taking a break from their caring role by organizing services for the care recipient. We can coordinate short term, planned or unplanned respite services. Relating to the MHRP, there are many flexible options to suit individual needs, from in-home respite to community based respite, social support, weekend retreats, transportation, domestic assistance, meals delivered and carer education and training. The team collaborates and works with carers on a case by case basis to understand and assess their individual needs and requests.

Almost three quarters of our registered carers are female (83%), aged over 50 years, accessing direct respite supports. This type of respite gives the carer a break through the provision of a substitute carer or activity for the care recipient. More than one third of carers are employed, almost two thirds are married, only one third are in receipt of a carer payment or allowance, one third are not in receipt of any Government pensions or benefits and almost two-thirds (64%) of carers provide more than 40 hours of care per week. Approximately 40% of all registered carers have a “high need”; they have been assessed as experiencing extreme difficulty managing their caring responsibility.

THE RECIPIENTS WE SERVICE

The Commonwealth Respite and Carelink Centre MHRP works with a range of vulnerable clients experiencing or at risk of ongoing mental illness. Clients present with a range of diagnoses such as anxiety, depression, schizophrenia, post-natal depression, bipolar, obsessive compulsive disorder. The program aims to “…provide increased opportunities for recovery for people whose lives are impacted by severe mental illness by helping them to overcome social isolation and increasing their connections to the community.” Australian Department of Families, Housing, Community Services and Indigenous affairs (2011)

Upon analysis of our program’s statistics (conducted June 2012) - there is a relatively even gender split amongst those being care for - 40% are female and 60% male. A staggering 88% are currently not in paid employment; 91% are co-resident with their carers and 61% of recipients have challenging behaviours which require support. 12% of clients are from a culturally and linguistically diverse background and 4% are from an Aboriginal or Torres Strait Islander background. Currently, young people (under 25 years of age) diagnosed with mental illness account for 52% of all recipients registered. As the program continues to grow it is predicted that this number will increase.

THE PROGRAM MODEL AND STRATEGIES

The Commonwealth Respite and Carelink Centre MHRP is built on a brokerage model; the program coordinator uses funding to purchase services from providers. In order to do this successfully, a lot of time has been invested in working in partnership with agencies to educate, meet client’s needs and address the gaps.

The MHRP coordinator assesses each carer’s eligibility and needs on a case by case basis whilst acknowledging that respite needs to be individualized as there is no one size fits all approach. From discussion with the carer, a respite request is formed, outlining what type of service is suitable, and how many hours are required. This request is then taken to an intake
meeting for team discussion and funding approval. The carer (and where appropriate, the recipient) is involved throughout the coordination of the respite care, and kept up to date with the services being booked. Where possible, services that the family are already linked in to are also involved. This is done to ensure continuity of care and reduce duplication of services. Respite should be complementary to any supports currently being received by a carer or recipient.

The FaHCSIA guidelines state that the following have been approved as eligible for respite funding:

- Respite including short term breaks from the caring role;
- Brokerage services for carers, families and young people based on needs assessment;
- Educational programs that increase knowledge, understanding and acceptance with the aim of increasing the carers capacity to better manage the impacts of mental illness such as mental health first aid, and carer capacity to engage in employment;
- Counselling to decrease anxiety and depression and promote self care;
- Peer support through groups or one on one support to sharing learnings about the nature of mental illness crises and behaviours associated with them, leading to relief for carers and building resilience;
- Advocacy services that strengthen and empower carers such as assisting carers maintain employment and support for young carers to stay in school;
- Information and referral to other community supports such as Indigenous and CALD services that are underpinned by service providers developing and maintaining strong collaborative networks in their community; and
- Social and recreational activities aimed at increasing the carer and care recipients social participation.

Australian Department of Families, Housing, Community Services and Indigenous affairs (2011)

The Commonwealth Carelink and Respite Centre MHRP aim to support the recovery journey and want the services organised to be as meaningful as possible.

**OUTCOMES**

The Commonwealth Respite and Carelink Centre MHRP have been in operation for more than five years. During that time, more than 75,500 hours of service have been delivered to support carers in different respite areas including mental health educational programs, host families, meals, domestic assistance and individualised respite services. A substantial amount of hours in particular have been allocated to community direct respite services whereby a support worker assist the person being cared for to achieve recovery based goals and commence their road to recovery. Examples of goals could include teaching lifestyle skills (for example catching public transport), companionship, education around mental health and well-being. Upon completion of service provision, the person being cared for is then linked into ongoing community support services for continuity of care and ultimately assists with improving the emotional, health, well being and quality of life of the carer.

As part of continual quality service provision and improvement, the Commonwealth Respite and Carelink Centre MHRP follows through with review of respite services to enable the team to focus on a customer feedback analysis. Based on the calculations derived from the MHRP feedback survey forms 2011-2012, 96% of carers found the respite support provided was useful and 97% of carers were satisfied with the respite provided. The below quotes are some examples of positive feedback received for services organised:
“...I don’t feel so scared and alone in my caring role anymore...”
“...A job well done. I did now know how tired I really was until last weekend’s respite. Thank you...”
“...We are thrilled with change of behaviour and response to their needs by both the service providers and MHRP in planning of respite and delivery of services...”
“...The help I received was very beneficial and much appreciated. Thank you...”

The Commonwealth Respite and Carelink Centre MHRP additionally collate good news stories that focus on the rewards of respite with the below two examples demonstrating best practice:

- A seventy-eight year old carer was recently referred to the Commonwealth Respite and Carelink Centre MHRP for respite. She has been supporting her daughter - now in her mid forties - for the last twenty years. There are no other family to support them, they live alone and are very socially isolated. Her daughter is linked only to a private psychiatrist, no other community based services or mental health clinics are involved. Over the last four months we have worked in partnership with local agencies and the family to link them in to appropriate services and support. The carer attended a carer education and training weekend where she was able to learn more about her daughter's diagnosis, how to cope, as well as make friends and relate to others in the same situation. The daughter has been receiving one on one support, firstly in home and then in the community. She has been attending a hearing voices network to understand more about her illness and interact with others in a similar situation. She now also volunteers at a local dog shelter.

- A carer providing support to a 45 year old female with complex mental health issues was referred to the Commonwealth Respite and Carelink Centre MHRP by a community service provider. The carer was highly stressed from caring responsibilities which was impacting on other parts of his life. Respite was needed urgently as the family were assessed as high priority. Community social support respite, meals and domestic assistance support were organized over a period of two months whilst regular reviews assisted in reducing the family's stress levels and alleviated crisis. We also worked with the family to re-establish some ongoing support with Home and Community Care services and local mental health services. The Commonwealth Respite and Carelink Centre MHRP received positive feedback regarding respite support provided and linkage to ongoing support services as it enabled carer to engage in regular social activities and improved his ability to sustain the caring role.

The Commonwealth Respite and Carelink Centre MHRP thereby recognise the importance of carer inclusion and the need to work in partnerships with carers to organise individualised respite breaks. This in turn leads to reduction in carer stress levels, improved relations with the person they care for and family functioning, carers better balancing their caring roles with other parts of their lives as well as an improved ability of to sustain their caring role.

All you need to do is call 1800 052 222 and talk to the team today.

ALL CRCC Programs Funded by:
Mental Health Respite Program FaHCSIA*
Carelink & National Respite Carers Program DoHA**
Young Carers Program FaHCSIA*
Respite for Carers of Young People with a severe or profound disability FaHCSIA*
* Department of Families, Housing, Communities and Indigenous Affairs
** Department of Health and Ageing.

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