



Hidden Carers – A Tale of Two Hats

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The Starting Point - A Personal & Professional Journey/Challenge



- When someone you love has a Gambling Problem
- When the profession you are engaged in has an obvious role to contribute
- When the health system you work for fails to recognise the issues
- When you are aware of others hurting and their lack of empowerment
- When the socio-political system seems not to notice

Wexler's Model

A Chart on the Effects of Compulsive Gambling on the Spouse



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 Training, Consultation, Evaluations,
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Life Pathways (Kalischuk & Cardwell, 2004)

- Transition
- Tension
- Turmoil
- Transformation
- Transcendence or Termination

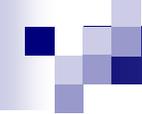
A theory which focuses on the individual experience contextually embedded within numerous systems including family, community and society



Theoretical Perspectives



- Systems Theory – assumes that an individual system is both a part and a whole - as is a family. (Wright and Leahey, 2000)
- When one family member changes then it follows that others are also affected
- Holistic Perspective – that humans are complex and multi dimensional beings influenced by physical , mental, psychological, social, spiritual and economic factors (Kaliscuk et al,2006).



NSW Health Carer Action Plan Priorities

- Carers are recognised and respected
- Hidden Carers are identified and supported
- Services for Carers and the people they care for are improved
- Carers are partners in care
- Carers are supported to combine caring and work.

Defining Carers



- “A Carer is a family member, friend, neighbour or other community member who provides care and assistance to another person, often in a regular and sustained manner, without payment other than in some cases a pension or benefit” (NSW Health Carer Action Plan 2007 – 2012)
- “Care” is generally accepted to be any combination of financial, emotional or physical support.

Who Do Carers Care For?

- “Carers Provide assistance to others including frail older people, people with disabilities, **people with mental health disorders, people with alcohol or other drug dependency**, people with dementia, people with a terminal illness, people living with HIV/AIDS, and people with a **chronic illness.**”

NSW Health Carer Action Plan 2007 - 2012



Problem Gambling Family Members...

Do They Care?

How PG Families Care

- Many are the first line of support on financial matters
- Provide emotional support to those those affected including person who gambles, nuclear and extended family
- Often are the primary source of information for others on the impact of PG on the family
- Often tend to be the primary researchers about the disorder and seek assistance earlier than the person who is gambling
- Take on additional roles and family responsibilities in the face of the “disability” of the person who gambles
- Seek additional financial resources (work/benefits) in order to maintain household and family.
- Often take on the long term financial management of the household

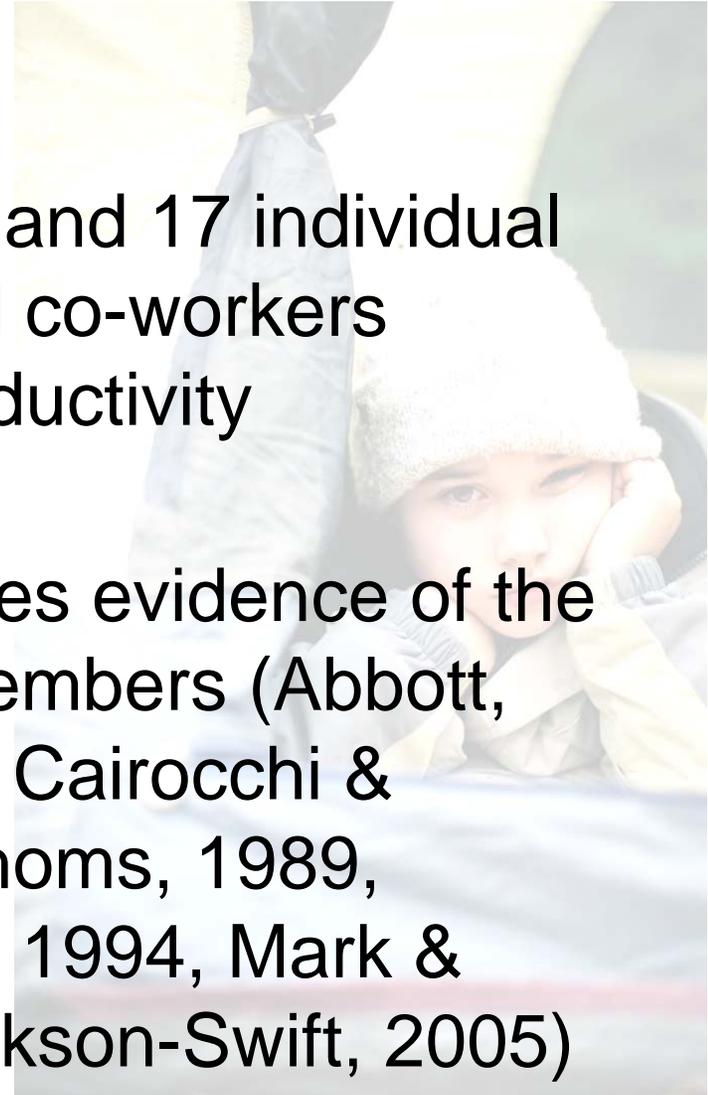
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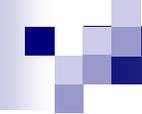
- Unlike New Zealand, problem gambling in many jurisdictions in Australia and particularly in NSW is not seen as:

“Core Health Business”

PG Impacts on Families

- Every PG affects between 10 and 17 individual including family members and co-workers (Lesieur, 1984, Australian Productivity Commission, 1999)
- Considerable research provides evidence of the negative impacts on family members (Abbott, 2001, Baeudoin & Cox, 1999, Cairocchi & Hohmann, 1989, Franklin & Thoms, 1989, Gaudia, 1987, Ladoucer et al, 1994, Mark & Lesieur, 1992, Tran, 1999, Dickson-Swift, 2005)





Most Common Family Problems

- Loss of household/personal money
- Arguments
- Anger & violence
- Lies & deception
- Neglect of family
- Negatively affected relationships
- Poor communications
- Confusion family roles & responsibilities
- Development of PG or other addictions within the family

PG and Family Health

Spouses:

- 84% of spouses considered themselves emotionally ill (Lorenz & Shuttlesworth, 1983)
- 47% Depression
- 14% Suicidal ideations
- 27% Confusion
- 44% Isolation/loneliness
- 30% Guilt
- 74% Anger/resentment
- 5% Helplessness/hopelessness
- 13% Ineffective parenting

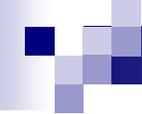
(Lorenz & Yaffee, 1998)

PG & Family Health

Children:

- Stress related conditions such as: asthma, allergies, headaches, insomnia, stomach problems (Lorenz & Yaffee, 1988)
- Negative feelings such as: abandonment, rejection, neglect, emotional deprivation, angry, hurt, sad, confused, isolated/lonely, guilty, helpless, anxious and depressed (various studies cited in Kalischuk, 2006)
- 25% children in the Lorenz & Shuttleworth study (1983) had significant behavioural or adjustment problems such as running away from home, committing crime, and engaging in D&A or gambling related activity.





PG Not A Health Issue?...

Who Did We Say Was In
Denial?

Problem Gambling - A Public Health Issue

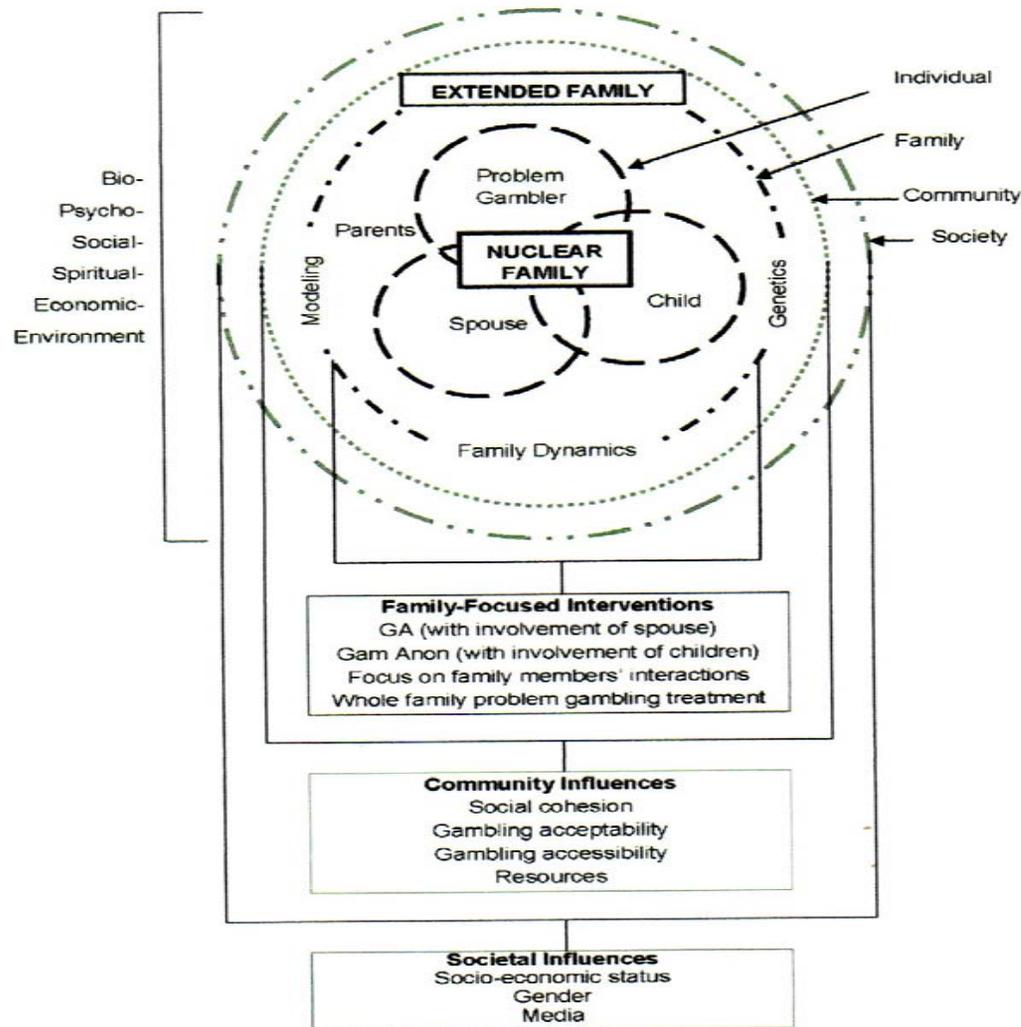
- There is no excuse not to recognise the health impacts of problem gambling on the person who gambles problematically and the families who care for them (the hidden carers).
- To do so denies the facts and results in the marginalisation of those affected and the denial of a main stream public health approach to the issue.



Identified Research Gaps

- Very little research **addresses** the impact of problem gambling on the family (Kalischuk, 2006)
- Those that do are limited to only the female spouse (Kalischuk, 2006)
- Limited number of studies into the effects of parental PG on children (Darbyshire et al, 2001)
- No Studies undertaken to discover the perspectives, understanding of the children and young people themselves (Darbyshire et al, 2001)

Kalischuk's Integrated Model For Understanding PG Impacts on Families



Gaps In Treatment for Families

- Considering the reported effects of problem gambling on family members there are very few targeted family treatment programs available and even fewer reported in the literature.
- Of those studies reviewed by Kalischuk in 2006, most focused only on the spouse and were limited interventions.

What Families Say...

- “If you have a problem you don’t want to spend all your energy finding help. It has to be easy”
- “I would like to see somewhere that families could go for help.”
- “I wanted to know what was going on in my husbands head. It some how didn’t make sense if I wasn’t allowed to join the (counselling) sessions. It was his problem but I was affected.”

Family Comments

- “Help organisations operate in their own little worlds – they won’t tell you about anyone else. I was treated like an outsider. They took no notice of me as a sister. My brother was perceived as ‘their Client’. His rights were considered paramount. Protecting my brother was their only priority. The supporting family was not addressed. My brother was isolated from the family. We as family were not treated as interested persons. They rarely made contact with us.”

Help Seeking by Problem Gamblers, Friends and Families: A Focus on Gender and Cultural Groups, McMillen et al, 2004.

Family Comments

- “I called Lifeline to seek help on how to deal with my husbands problem. They weren't very helpful. They didn't refer me to anybody and advised that they can only do something if my husband is willing to take counselling.”
- “I called lifeline. They told me they can't do anything, he has to first hit rock bottom before they can do something – they basically told me to leave him...”

Help Seeking by Problem Gamblers, Friends and Families: A Focus on Gender and Cultural Groups, McMillen et al, 2004.

Family Comments

- “The people I rang weren't helpful at all. It was frustrating and used a lot of energy. I wish he had a drug problem- then I would have found help.”
- “I think there should be more advertising out there to tell families where to find help. This is really missing.”

An Interesting Irony...

- “I have found support with Carers Australia. I meet with them every three months. It helps to talk the problem over. I have been offered support groups by Carers. It feels good to support my brother. It is energising.”



The Myth of Natural Recovery

Natural For Who?

Lack of Family Needs Assessment



- In researching the literature for this paper, I could not find one study whereby family members had been asked:

“What do you see as your own needs for support or intervention?”

- Nor any interventions which had set out from this basic health promotion premise of - find out what the community/client needs, then address that need. **As stated:**
- “The few studies that do address the impacts of problem gambling on the family often do so from the vantage point of the problem gambler rather than the family member” (Kalischuk,2006).

What Do PG Family Members Need?

- Respect
- Recognition
- Valued as a team member in the journey of recovery
- Their own needs assessed
- Timely information
- Knowledge about the disorder
- Ideas on how to protect and care for themselves and other family members in the journey
- Practical ideas on how to care for the person they love whilst respecting their autonomy and independence
- Support with relationship impacts and skills to deal with the impacts on others
- Financial and legal support
- Assistance to plan for the future
- To be heard and listened to
- To be included

Future Directions



- “It is important to ask, what is it like to live in a family with a problem gambler for the children, spouse and extended family members?”
- “We need qualitative research to explore not just the documented effects but actual issues and experiences to fully understand problem gambling and its impact on families”
(Kalischuk,2006).

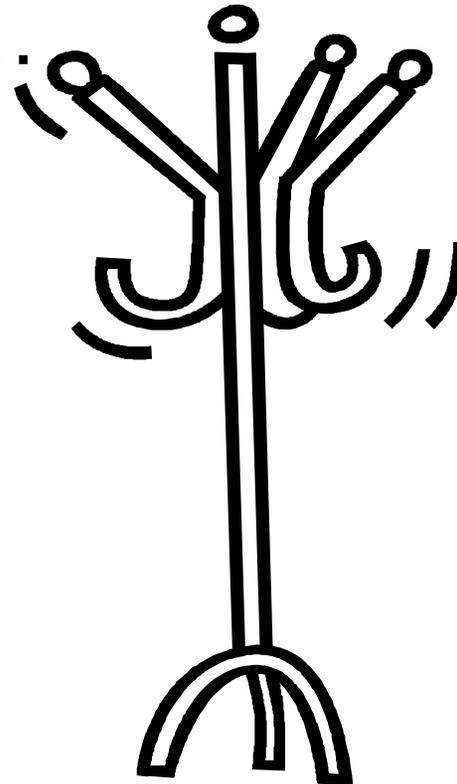
Implications for Practice



- Start with the family (system) who are “experiencing” a gambling problem (not just the “problem gambler”).
- Assess “family” needs
- Recognise the negative impacts but also the strengths and resilience of families
- Build a variety of modalities for working with **all** family members into the package of options for treatment/support
- Start where the people are – which is rarely sitting in your treatment office.

A Final Personal Thought...

In juggling, multiple-hats it has been suggested to me that one of these might be useful



However...

- I prefer the words of Joe Cocker....



“You Can Leave Your Hat On”

