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Overview

- Life, Love and Laughter
- Bio-psychosocial-cultural approach
- Observations from practice
- Literature review
- Our vision support group
- My PhD & Future directions

- Lack of empirical data on life, love and laughter (LLL)
- LLL some of the core ingredients of mental health (MH)
- How do people who are DB experience LLL?

LIFE

- “Can we keep working, do people really respect you?“
- “All people face challenges and question themselves but can people with disability break these shackles of doom and gloom just as easy as other people without disabilities?“

LOVE

- “Will my child love me regardless?”
- “Is it possible to have a long term relationship without being so dependent on another”

LAUGHTER

- “ I hardly ever laugh”
- “First sign of depression or states of anxiety is when life has no fun. Where did it go?”

Bio-psychosocial-cultural Approach

- Physical factors
- Understand the whole person e.g intellectual, personality and psychological
- Social environment of person/family
- Impact of culture (identity and meaning)

Organizational Issues

- MH is central to practice but not talked about explicitly
- Culture of silence

Lack of:

- Time to discuss MH issues
- Staff training
- Clinical guidelines and training packages for professionals

Observations from Direct Practice

- Australian DB community has a unique culture
- No empirical research exploring the meaning and impact of DB culture on MH
- Positive and negative impacts on MH
- Not all people identify with DB culture and community

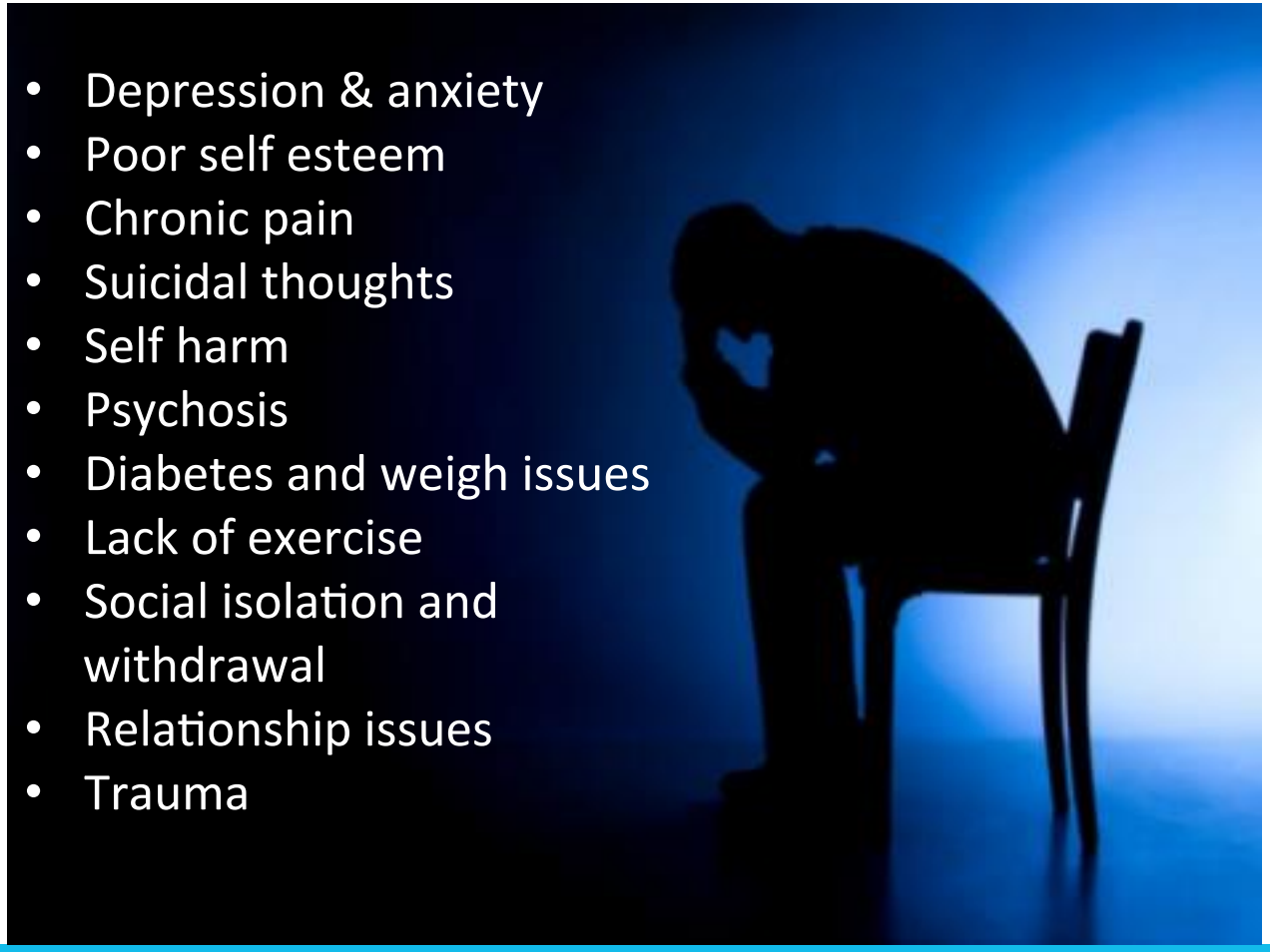
Stigma, Shame and Silence

- Few DB had ever talked to another peer about MH
- Many use words like “crazy people” “mental people” “they are mad”
- Embarrassed about accessing support
- Worried that people will find out

Lack of Mental Health Education

- Lack of education about MH issues
- DB Services geared towards disability not MH
- MH services not equipped to respond to DB
- Few targeted programs and services

Common issues associated with Mental Health



Life, Love and Laughter

Systematic Review of the Literature

Search criteria:

- DB adults, and
- Mental health and wellbeing, or
- Culture and community
- No language or year limiters
- 10 Academic Databases

- Authors and grey literature sourced
- Over 1,500 articles screened
- Aprox 120 articles included in the review

Results of my Systematic Review of the Literature

- Majority of the literature: children, education and vocational outcomes, technology, O&M, communication, sign language etc
- Lack of data on DB MH
- No best practice DB clinical guidelines or training programs
- Range of methodological issues in the data

Themes that Emerged Within the Literature

- No empirical study exploring DB culture, community, MH & LLL
- Lack of DB authors and DB perspectives
- Lack of studies reporting on: DB MH assessment diagnosis and interventions
- Most interventions, programs and services not empirically evaluated

Pathologizing DB

- "Deaf and blind psychotic patient" (Peterson, 1977)
- 21 DB persons were found to have 3-11 psych problems (No DSM, clinical assessment or DB perspectives (Hassinen, 2013)
- "28 year old DB man periods of mild and extreme rage, hitting & biting (Jacobsen, 2009)

Lack of a Voice

- Hersh (2013) semi structured interviews, communication & isolation, gatekeepers reduce the control DB
  (some interviews interpreted by family members)
- Jacobsen (1983) reducing self injurious and aggressive behaviors in deaf-blind person through overcorrection

(No ethics, consent, how did staff feel, only 1 psych perspective)

Negative Attitudes

- DSI causes reduced morality (Schnider, 2011)
- Negative societal attitudes towards disabilities and DB people specifically create stigma and barriers (Brennan, 2007)
- Aging population, more is needed, they are deserving, not just part of life (Lidoff, 2003)
- Miner (1995) pitty prevents DB from being seen as real people, don't assume symptoms are "normal" for DB

Does DB Culture Exist?

- No DB culture in UK
- DB do not meet regularly
- absence of unique language (although aspect of touch is unique)
- Some DB do not identify as being DB
- "Pure" Deafblind culture can only exist with CDB
- Cannot define "pure" CDB culture in meaningful way due to complex and profound disability
- ADB have influences of hearing and sighted world; they are not "pure" DB (Barnette,2007)

DB Perspective on Culture

- DB is unique, gives DB people identity and pride
- Despite the diversity in language, communication style, degrees, types, causes and age of onset of DB people stick together and have a “community”
- The very diversity in communication modes constitutes a “culture”
(Pope, 2005)

Deafblind Culture?

- DB have pride, can be empowered, positive attitude of “I am deaf-blind so what
- “I can still enjoy my life and not let my disability limit me”
- DB community provides a place for acceptance, pride, role models and self-esteem
- DB community require organisations to help facilitate this cultural experience (Pope,2005)

More Research is Needed….

- Does DB culture exist in Australia?
- What does LLL mean to DB, and the links with MH?
- How does culture and community impact MH?
- How can services and agencies promote DB culture & LLL?

Our Vision Support Group

- Create a safe space to share and form friendships,
- Challenge myths and stigma,
- Psycho-education,
- Build self-esteem, confidence and self advocacy skills,
- Self care and relaxation skills,
- Reduce and manage MH issues

Our Vision Support Group

- “If people are fully deaf and blind and confident, its so interesting to meet them”
- “Her attitude is: ‘I'm deaf, and I’m blind” SO!
- “I envisage change, and I want the Deafblind community recognized as a culture”
- “I belong to both communities”

Our Vision Support Group

- “How do we get our stories out and educate people about the DB community”
- “The Deaf community don’t always understand our culture”
- “When I was in the Deaf community I didn't’t feel like a strong member”
- “We’re in the same world”

Our Vision Support Group

- "It's easy to isolate yourself and stay at home, but you need to go out and communicate with people and share our stories"

- "We should all show compassion and support each other, because its exhausting using tactile"

Our Vision Support Group

- "We need to start talking positively about Deafblindness. I've just only realized that I've been talking negatively"
- I think we really need to start talking positive about things, become role models
- "I'm interested in how we change the negative self talk we have, change that into a positive. I don't know how"

My PhD & Take Home Message

- Utilize the Bio-psychosocial-cultural approach
- Lived experience of DB culture & community (LLL)
- DB experience of MH, services, professionals & organizations
- Survey experts (professionals and people who are DB) in the field “what is best practice?”
- Design and evaluate a clinical best practice frame work & training package

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