

I am the Warrior

Lived Experiences of the Mother and Carer roles and
Mental Health Group Membership



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Background

- From institutions to community-based services
- From bio-medical model only to Recovery and multi-disciplinary approaches
- Increased roles of responsibility for the individual (service user), and their loved ones in recovery
- In 2002, 1.5million caring for a family member with mental health difficulty (ONS, 2002)
- Study across 22 countries showed average time caring was 15 years, 22 hours per week (2015)
- Similar trends in Ireland with increasing numbers of family carers (2011 Census)
- Most of whom are parents (2009 Survey)

Background

- Caring for another can be an emotionally and physically demanding role
(McCann, Bamberg, & McCann, 2015)
- Carer Burden can include
 - Objective Burden: financial, impact on daily tasks, health, energy
 - Subjective Burden: Carer's perception of burden, social, emotional, psychological impact
(Hoenig & Hamilton, 1966)
- Worry, loss, grief, uncertainty, shame, stigma, guilt, responsibility, blame, anger, resentment, overwhelmed, consumed with the role
- Services and professionals as both a support and burdensome
- Other dimensions
 - For some, improved relationship with their loved one
 - Feeling more resilient, purposeful
 - Opportunity for growth, development, learning
 - Role as facilitated by feelings of love, patience (Lowyck et al., 2004; McCann et al., 2015)

Not only a Carer, but also...

- Consuming nature of a Caring-role
(Greenwood & Mackenzie, 2010; Wynaden, 2007)
- Dual Roles of Partner-Carer, Father-Carer, Sibling-Carer
- Mothers
 - Highest proportion of carers
 - More time caring, most contact with services, most likely to participate in groups
(Hanson & Rapp, 1992; Marsh, 2001; Pickett-Schenk, 2003)
 - Cultural representations of the “Good Mother”
 - Self-sacrificing, protecting vulnerable children
 - Devote time, energy to meet their child’s needs
(Sousa, 2011)
 - Not unlike Carers
 - Place needs of loved one before their own
 - Expectation in health system and services also

Background

- What helps?
 - Family Consultation
 - Family Education
 - Family PsychoEducation
 - Family Counselling/Therapy
 - Support Groups

(Marsh, 2001; Lefley, 2001)

- Support Groups
 - Information, open discussion, support, a platform
 - Importance of giving and receiving in groups

(Dixon et. al., 2004; Heller et al., 1997)





Mental Health Trialogue

- Brings together service users, professionals, and family members in an open dialogue conversation
- Backgrounds, experiences, and expertise of all attendees are recognised
- Meetings are facilitated and organised by service users, carers, and professionals
- To develop understanding of mental health issues
- Community perceptions of mental health
- Transform thinking on developing better services and healthy communities



This Study

Question

Participants

Method



- The lived experiences of mothers of adults with mental health difficulties
- Their experience of being in Trialogue
- Participants
 - From 6 Trialogue groups across Ireland (Dublin, Cork, Mayo, Meath)
 - 8 mothers participated
 - Aged 45 – 57
 - Attending Trialogue for 4 months to 3+ years
 - 7 were living with their adult child
 - Children aged 20 – 39
 - Difficulties included mood, psychosis, suicidality
 - Onset between 1 – 10+ years

Interpretative Phenomenological Analysis (IPA)

(Smith, Flowers & Larkin, 2009)

- Involved in-depth, semi-structured interviews (1.5-2 hours)
 - Motherhood
 - Experiences regarding mental health
 - Trialogue
- Detailed examination of the lived experiences of these m
 - how they interpreted their experiences, gave meaning
 - and my interpretations of what they told me



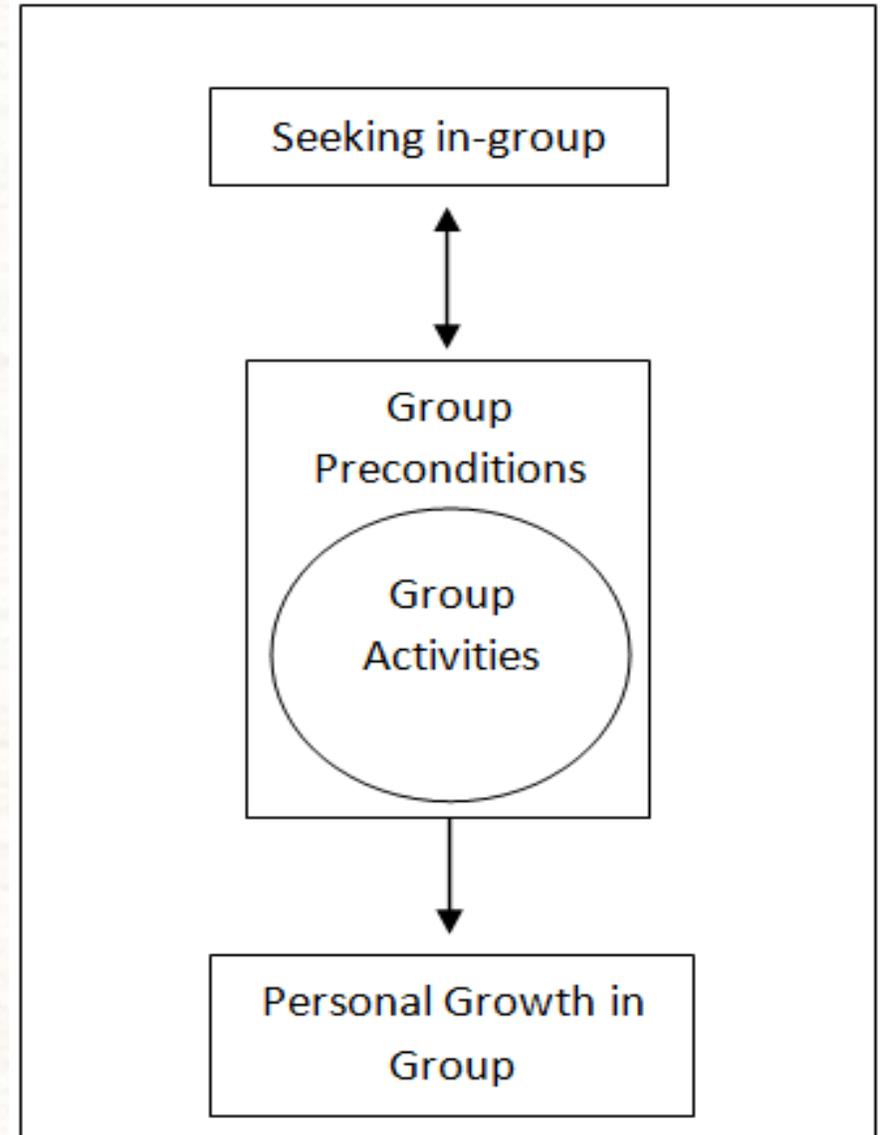
Findings



Superordinate Themes	Subordinate Themes
<i>Transformational Group Meanings</i>	Seeking in-group Group Preconditions Group Activities Personal Growth in Group
<i>Negotiating Trauma, Relationships and Roles</i>	Nature of Trauma Beliefs and Expectations about Motherhood and Caring Relationship to Self Renegotiating the Mother-Child Bond
<i>Dynamics of Power</i>	Services Society Mental Illness

Transformational Group Meanings

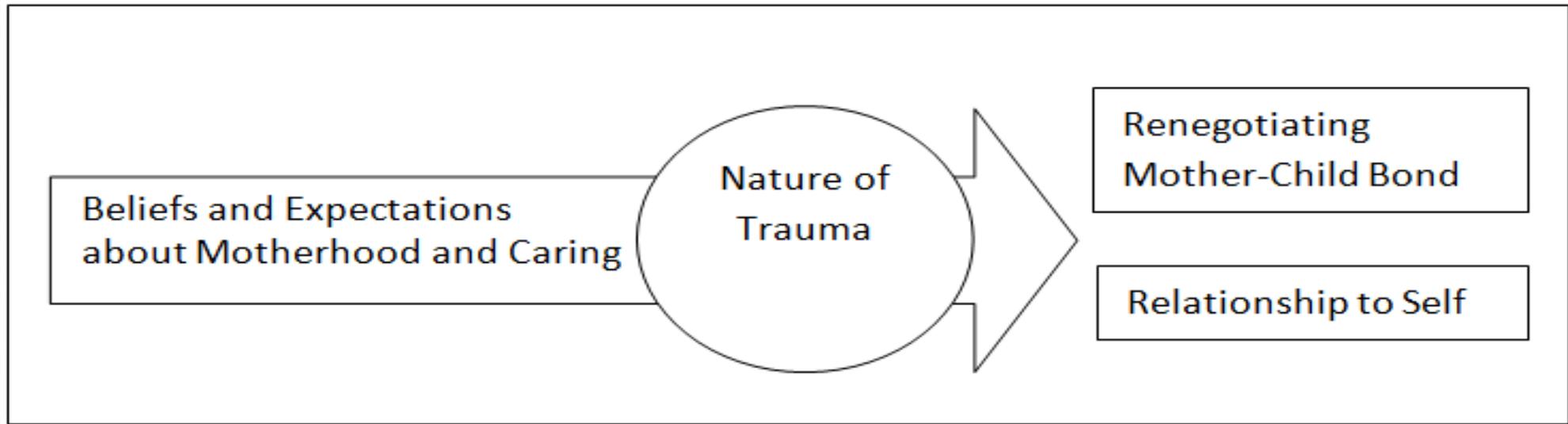
- Seeking in-group
 - Reduced isolation, commonality, shared beliefs
- To work, the group must have...
 - Respect, confidentiality, equality, balance
- Activities within that environment
 - Sharing, listening, validating, supporting, information sharing, accessing perspectives
- Their own journey
 - Anger, personal growth, impact on their behaviour and relationship with child, taking on new roles



- “You really feel like you’re not in isolation, and a certain amount of bonding happens, because of the commonality” (Sarah)
- “Triialogue is breakin' down them barriers, and openin' up peoples' minds to...to recovery” (Miriam)
- “It was mind blowing, that in this room, we had service users, professionals, and family members, all talking about the same thing in a very non-threatening way” (Sarah)
- “looking back I think I was quite narrow-minded in the way I thought about things you know, I certainly would hope I would be much more broad-minded now, more open to things” (Emma)

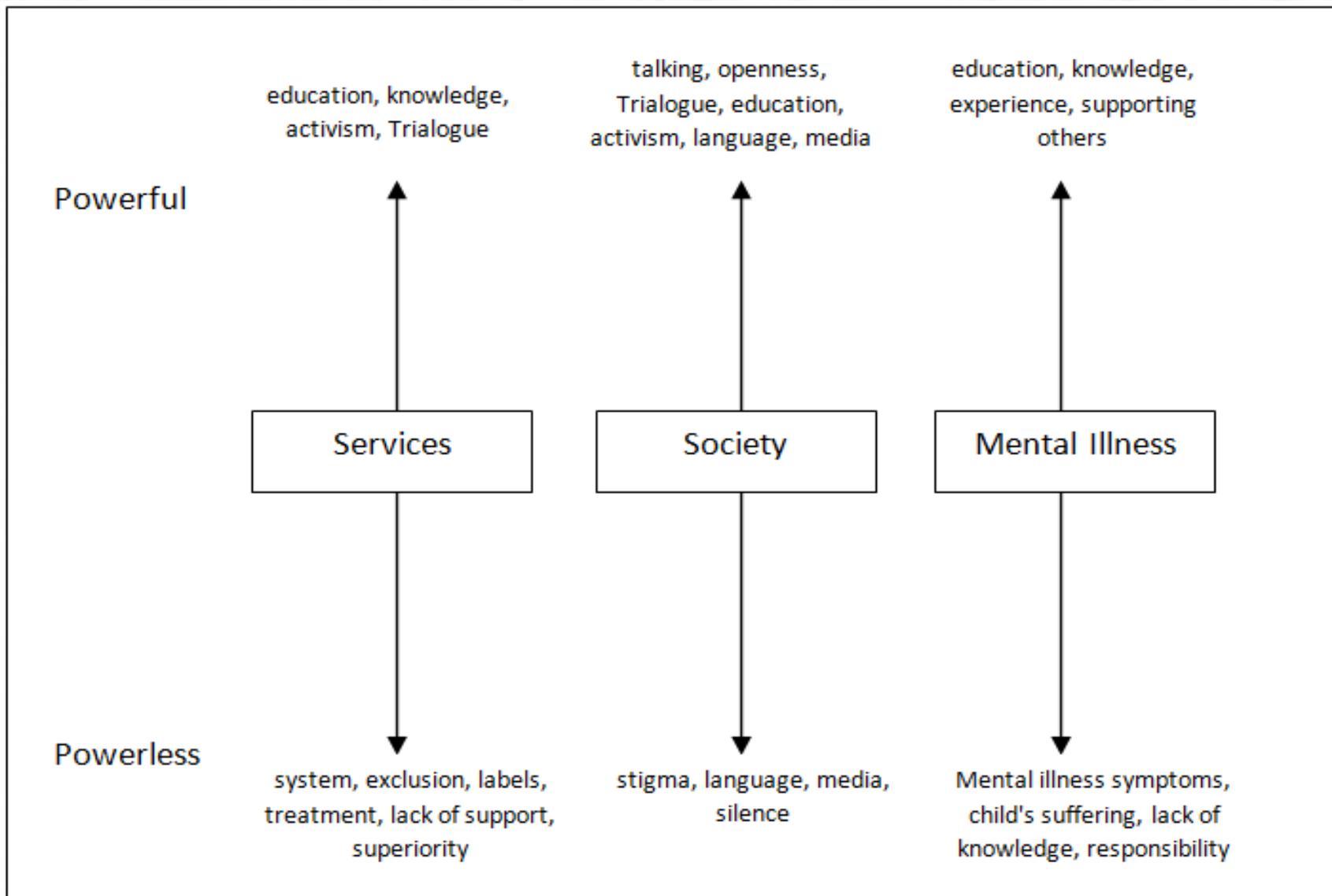
Navigating Trauma, Relationships, and Roles

- Child's mental health difficulties as a Trauma
- What does it mean to be a Mother or Carer?
- Separating and joining with their child
- Their own developmental path



- “I do believe that something died inside me that day. I'll never get over, I never got back from that day.” (Miriam)
- “And something woke up for me, it was the primal instinct of a mother“
- “If you have it in you to be a mother, you don't ever stop trying to do your best to help them along the road“ (Megan)
- ““But I don't need any carer, you're my mum, I just want you to be my mum.' I said, 'Yeah, I am your mum.'“ (Sarah)
- “I think I've grown to be who I was meant to be“ (Rebecca)
- "I'm so angry just for us not to be listened to, and taking on board what we have to say, we are just a feckin' load of numbers“ (Rebecca)

Dynamics of Power



- “The diagnosis was always changing. And the tablets were always changing. The unfortunate thing is, you believe it.” (Rebecca)
- “I'm equal to them. And I had said many times "I'm actually not your patient, doctor. I'm actually a mother. You're a mother, so I'm asking you as a mother. You know, obviously I want your professional view, but I'm asking you also as a mother. Remember that's my son you're talking about.” (Miriam)
- "they just don't talk down to you as much, if you have a bit of knowledge and can challenge their beliefs“ (Rebecca)
- “If it's something that's going to help my daughter and help my family. And those other people that were the hospital that had nobody to fight for them. If I can be that voice, if I can help those people, yes, I will do it. Absolutely 100%.” (Sarah)
- "the telly, media, newspapers, doctors, you know they make you fearful of people with mental health difficulties. And really they're the ones with all the power“ (Rebecca)
- "And my way was education. My coping skills was education.” (Miriam)

What have we
learned?



- Recognising this group, affording them equal respect
- Respecting their role and identity as a Mother, not assuming everyone identifies with “Carer”
- Reclaiming power - knowledge
- Anger, self-compassion, not ashamed
- Warriors and Activists
- Trialogue has the potential to bring a more powerful voice – empowerment and change
- But all voices must be heard equally
- Encouraging attendance!

The Voice of the Mothers

“I am the warrior, and I will fight to the last breath for my children, I will do anything that it takes to look after my children”



“So yes, I’ve got strength, I’ve got the voice, I have shared, and I have listened, and I have probably shared the tears as well, my tears and other people’s tears. We’ve shared the tears.”

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Information on Trialogue

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<http://www.trialogue.co/>

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