

Recovery at the End of Life:

Development of a Group Psychotherapy Intervention for Persons with Life-Limiting Illness

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Goals of Presentation

- Review of recovery model and its application to end of life care
- Describe how the EOL group was conceived and developed
- Description of the group intervention
- Outcomes, challenges, next steps



Recovery Model-A Primer

“Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.”

-SAMHSA, *National Consensus Statement on Mental Health Recovery*

Recovery Model-A Primer

- Historical framework and evolution
 - Emerged in 1990s in the context of SMI
 - Spurred by consumer movement
 - Move away from medical model of mental health problems as chronic and untreatable
 - First credited to Anthony, 1993
 - Most English-speaking countries have now adopted recovery language in public policy
 - Cultural transformation

Clinical Applications of Recovery

- SMI
 - Positive outcomes through empowerment
- Substance use
 - Oxford House model
- Trauma
 - Recovery-oriented groups
- Gerotranscendence



Other EOL Interventions

- Supportive
- Empirically supported interventions
 - Dignity Therapy (individual)
 - Mindfulness-based stress reduction (individual)
 - Meaning-Centered Group Therapy
 - Only group EST for this population to date

Recovery and EOL Care

- A Paradox?
- Ragins (2006) applied recovery principles to treatment of chronic illness
 - Chronic illness model applied to life-limiting illness
- Similarities of this population to other contexts
- Important differences
- Limited choices of EBTs at end of life



Group Development

- Content and structure
 - Elements of recovery model
 - Relevance to this population
- Power point presentations
 - Defining elements of our model
 - Hope
 - Meaning
 - Identity
 - Secure base
 - Empowerment
 - Coping strategies and tools



Group Development

- Measuring outcomes
 - Quality of life
 - Mood
 - Anxiety
 - Fidelity to Recovery Model



Quality of Life Measure

- **Missoula-Vitas Quality of Life Index**

(MVQOLI-Byock & Merriman, 1998)

- 15-item and 25-item versions
- Five QOL Domains:
 - Symptoms: Perceived level of physical distress
 - Function: Perceived ability to perform accustomed functions and activities of daily living
 - Interpersonal: Perceived quality of one's relations with family and friends
 - Well-being: Subjective sense of wellness; experience of contentment
 - Transcendence: Experienced meaning or purpose in life

Quality of Life Measure

- For each dimension, patients report:
 - Assessment: Measurement of status
 - Satisfaction: Acceptance, mastery
 - Importance: Impact on overall QOL
- Self report based on **patient's** subjective experience
- Excel files allow monitoring progress

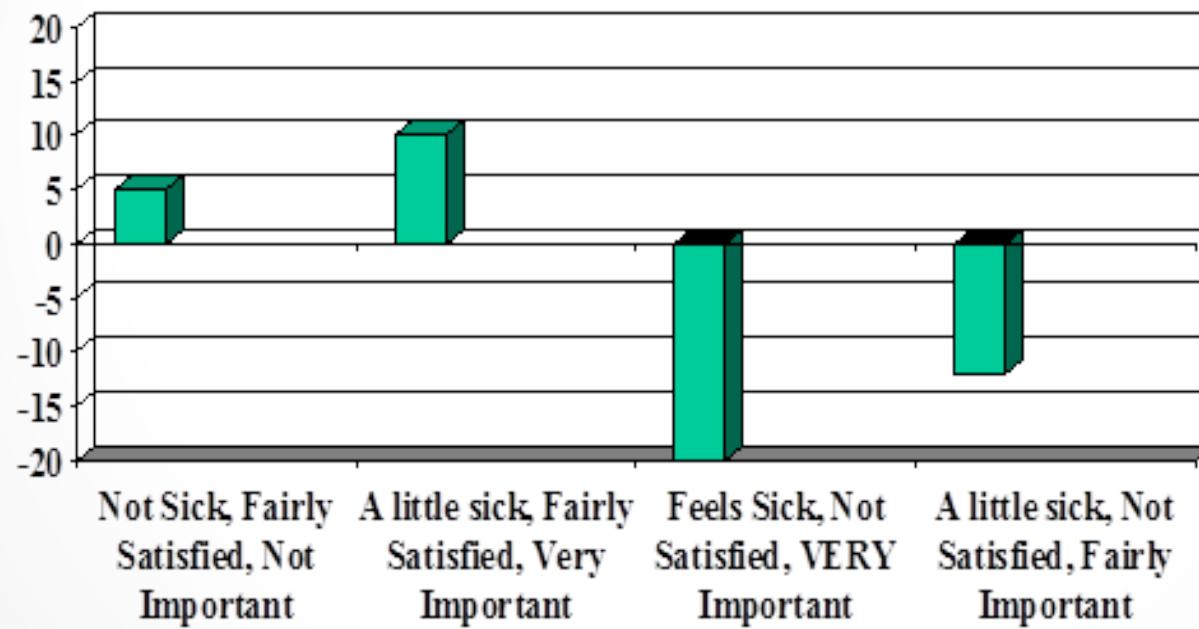
MVQOLI Dimension Scoring

Assessment -2 to +2

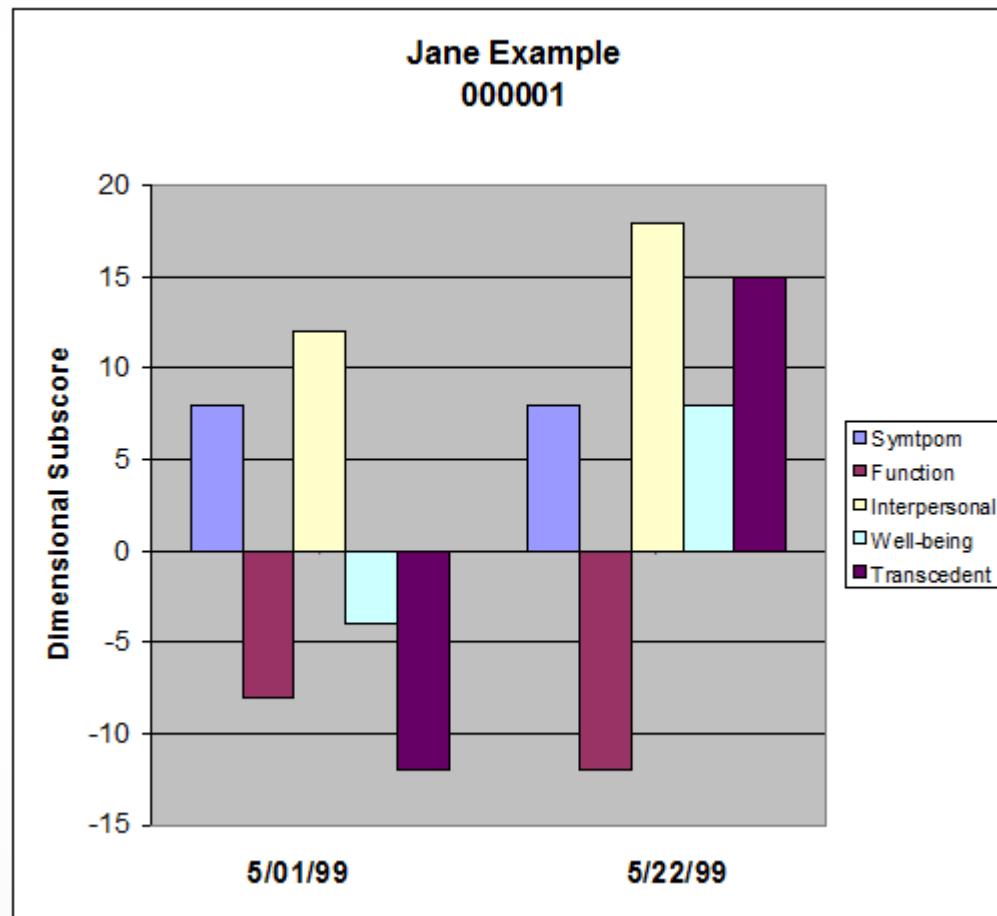
Satisfaction -4 to +4

Importance 1 to 5

(Assessment + Satisfaction) X Importance = QOL in each dimension



MVQOLI Profile (from Manual)



Symptom Measures

- PHQ-9
- GAD-7

PHQ-9 Depression

**Over the last 2 weeks, how often have you
been bothered by any of the following problems?**

(Use “✓” to indicate your answer”

	Not all	at Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things.....	0	1	2	3
2. Feeling down, depressed, or hopeless.....	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.....	0	1	2	3
4. Feeling tired or having little energy.....	0	1	2	3
5. Poor appetite or overeating.....	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down.....	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.....	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual.....	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way.....	0	1	2	3

GAD-7 Anxiety

Over the <u>last 2 weeks</u>, how often have you been bothered by the following problems?		Not at all	Several days	More than half the days	Nearly every day
<i>(Use “✓” to indicate your answer”</i>					
1.	Feeling nervous, anxious or on edge	0	1	2	3
2.	Not being able to stop or control worrying	0	1	2	3
3.	Worrying too much about different things	0	1	2	3
4.	Trouble relaxing	0	1	2	3
5.	Being so restless that it is hard to sit still	0	1	2	3
6.	Becoming easily annoyed or irritable	0	1	2	3
7.	Feeling afraid as if something awful might happen	0	1	2	3

RECOVERY ASSESSMENT SCALE-EOL VERSION

Below is a list of statements that describe how people sometimes feel about themselves and their lives. Please read each one carefully and indicate to what extent you agree or disagree:

1 Strongly disagree

2 Disagree

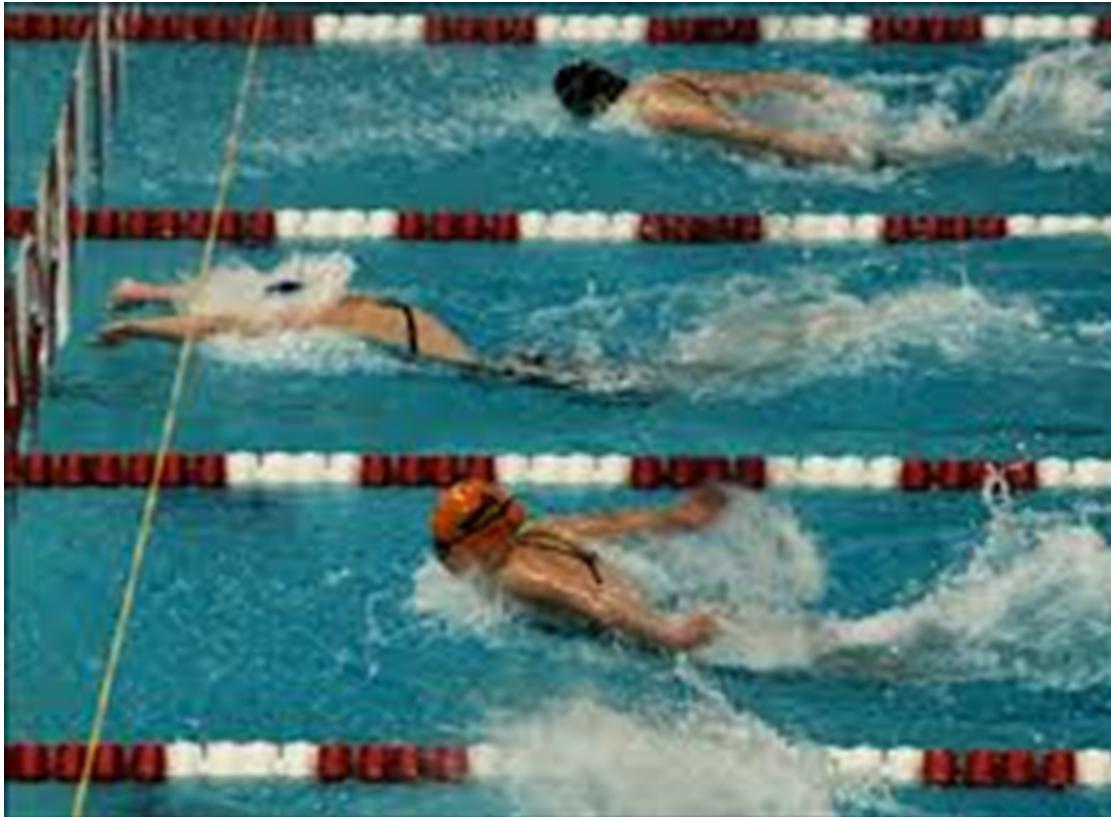
3 Neither agree or disagree, or not sure

4 Agree

5 Agree strongly

- 1. I have a desire to succeed**
- 2. I have my own plan for managing my illness**
- 3. I have goals in my life that I want to reach**
- 4. I believe I can meet my current personal goals**
- 5. I have a purpose in life**
- 6. Even when I don't care about myself, other people do**
- 7. I can handle what happens in my life**
- 8. I like myself**
- 9. If people really knew me, they would like me**
- 10. I still have good things to look forward to**
- 11. I'm hopeful about my future**
- 12. Coping with my illness is not the main focus of my life**
- 13. My symptoms interfere less and less with my goals in life**
- 14. I spend less time managing my symptoms than I used to**
- 15. I know when to ask for help**
- 16. I am willing to ask for help**
- 17. I ask for help when I need to**
- 18. I have people I can count on**
- 19. Even when I don't believe in myself, other people do**
- 20. It is important to have a variety of friends**

Why “Swim To The Wall”



Group Development

- The session format
 - Intro of topic
 - PPT presentation
 - Exercises
 - Group discussion
 - Debriefing if needed



Group Development

- Materials
 - Notebook
- Exercises
 - Worksheets
- Supplemental materials
 - David Oliver videos
- Coping toolbox
 - Relaxation CD



Group Development

- Recruiting
 - Outpatients
 - Inpatients
 - Community partners
- Marketing
 - Staff buy-in
 - Flyer
 - Brochure (in development)
 - Presentations
- The launch



Group Sessions

- Session 1-Introduction
 - Session topics introduced
 - Recovery model introduced
 - Session format
 - Group rules
 - Introductions
 - Completing outcome measures

Group Sessions

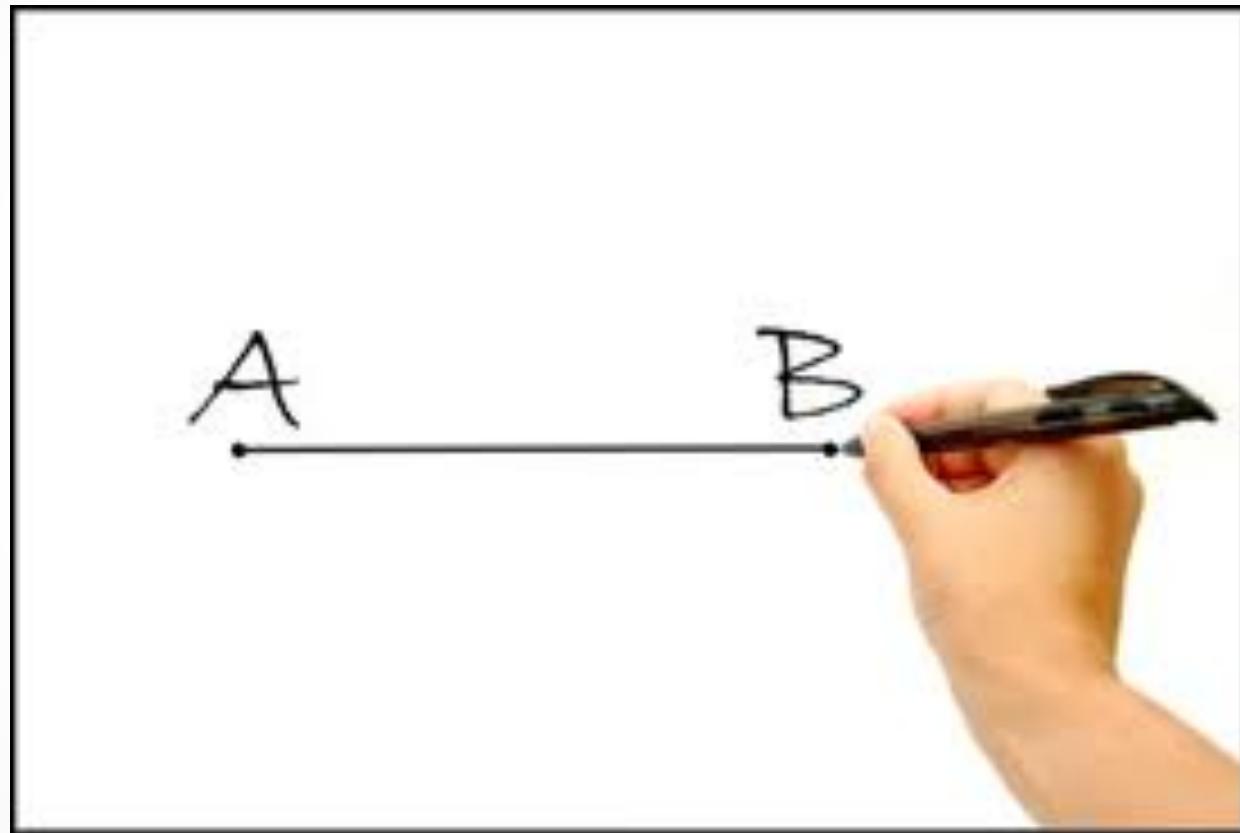
- Sessions 2-3: Hope
- Hope operationalized
 - Snyder model
 - Goals
 - Pathways
 - Self-efficacy
 - Trait Hope Scale
 - Worksheets

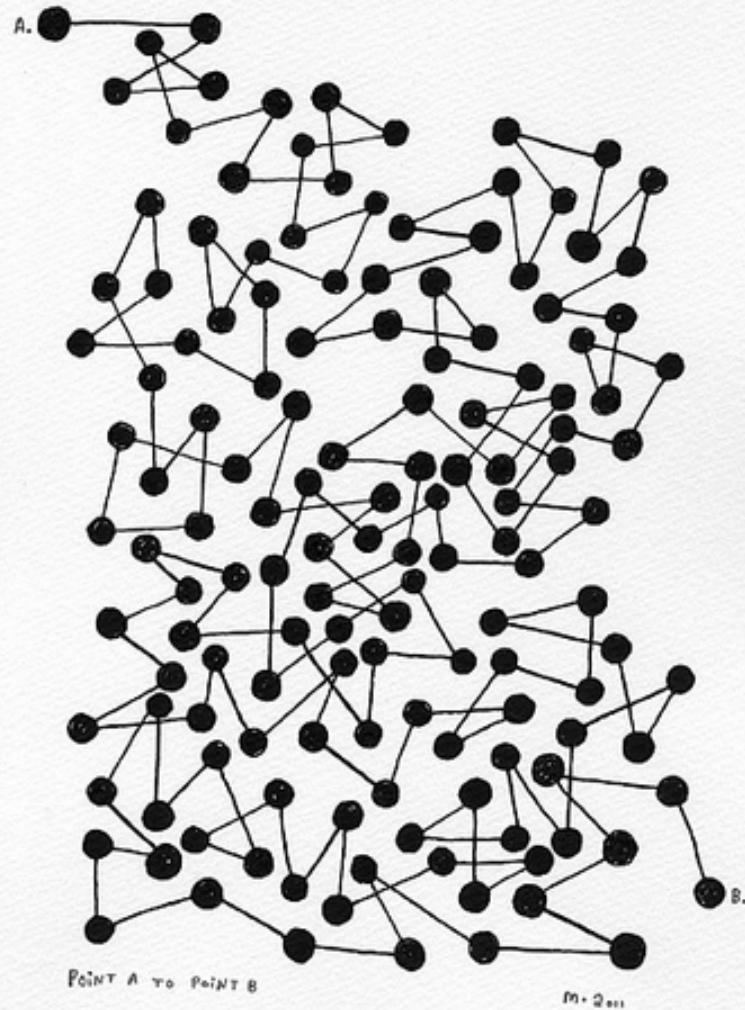


Hope

NEXT EXIT

Elements of Hope-Pathways

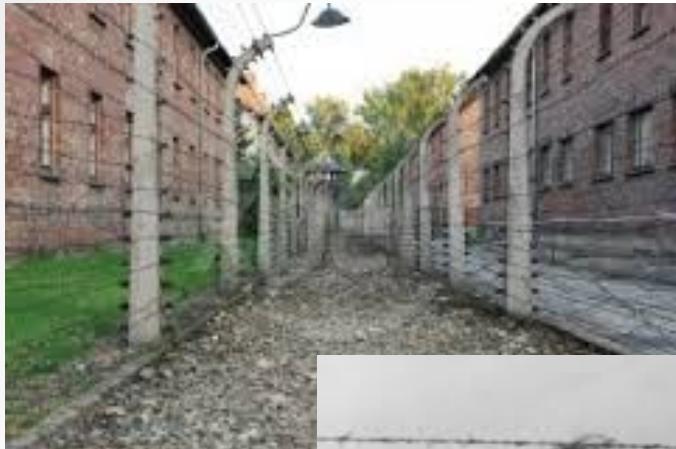




Group Sessions

- Session 4-Meaning
- Drawn from narrative, existential concepts
 - Frankl
 - Assumptive world
- Emphasis on meaning reconstruction in EOL context





“He who has a ‘why’ to live can endure almost any ‘how’
-Nietzsche



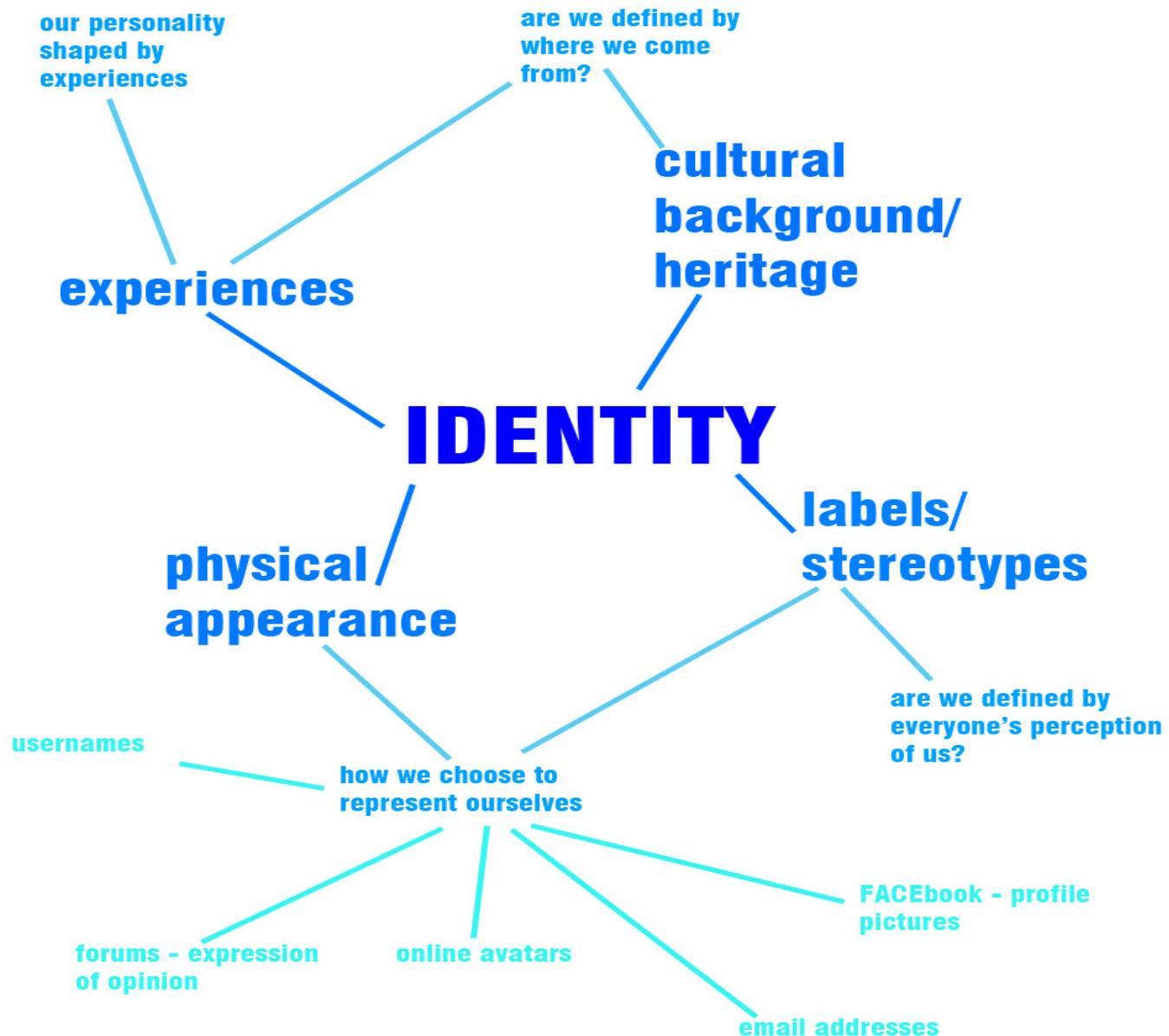
LIFE ISN'T ABOUT
FINDING YOURSELF.
LIFE IS ABOUT
CREATING
YOURSELF.

UNKNOWN

Group Session

- Session 5-Identity
- How does illness affect our identity?
 - Changes the way others view us
 - Changes our social contacts
 - Changes the way we view ourselves
 - A way in which others define us
 - A way in which we define ourselves
- Positive or Negative?

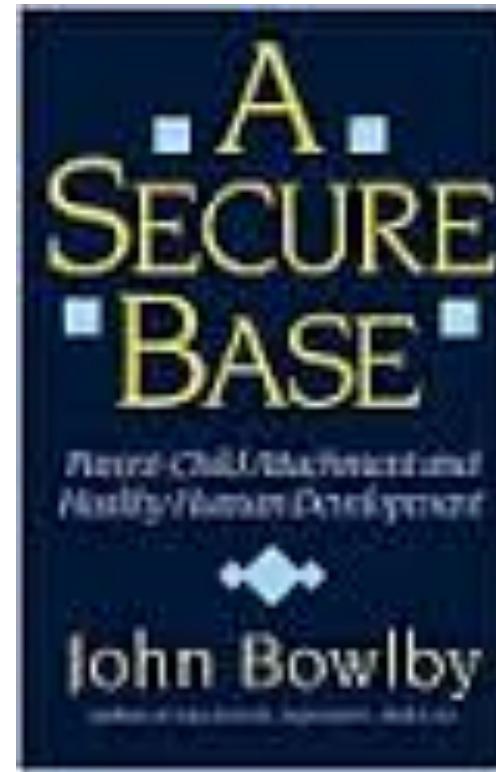
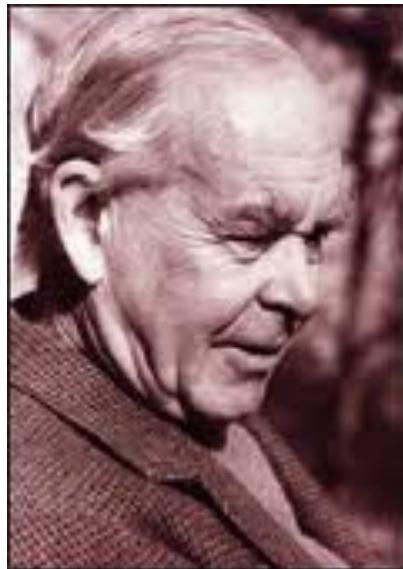




Group Sessions

- Session 6-Secure Base
 - Attachment theory
 - Military analogies were particularly helpful
- Sources of security
 - Family
 - Friends
 - Financial
 - Formal support systems
 - Beliefs/Faith base/Spirituality
 - Knowledge base
- Threats to security
 - Illness
 - Uncertainty
 - Lack of support system

John Bowlby-Attachment



Establishing a Secure Base



Group Sessions

- Session 7-Empowerment
 - Empowerment is:
 - Recognizing and respecting what you need and want
 - Identifying strengths
 - Elements of empowerment:
 - Having decision-making power
 - Having access to information and resources
 - Having a range of options from which to make choices
 - Assertiveness
 - A feeling that the individual can make a difference
 - Increasing positive self-image
 - Sources of empowerment
 - Goals (Hope, Meaning)
 - Identity
 - Knowledge of resources
 - Secure base
 - Social support





Group Sessions

- Sessions 8,9-Coping Skills
- Assessment of coping skills that patients already have
- New skills
 - Relaxation techniques
 - Mindfulness skills

Group Sessions

- Session 10-Putting it all together
- Summary of previous sessions
- Impressions and feedback
- Post-intervention measures



What We Learned

- Barriers to recruitment
- Barriers to participation
 - Travel
 - Illness exacerbation
 - Persons at various stages of illness progression
- Getting off topic
 - Responding to emergent issues
 - Responding to deaths of group members



What We Learned

- Format sessions to stand on their own
 - Feedback from national CLC providers call
- Flexibility with content
- Call-in members
- Too many facilitators
 - Learned from group member feedback
 - Limit to no more than two per session
- Using individual differences for therapeutic benefit

Outcomes

- Participant responses
 - “Safe Place”
 - “A lot to learn here”
 - “Marketing” suggestions (bring cookies)
- Plans for further data collection
- Plans for dissemination

Outcomes

- Preliminary Data-Issues
 - Missoula-Vitas needs veteran norms
 - Validation of recovery measure
 - Effort, willingness to participate in measurement
 - Building a critical mass to draw power
 - Dissemination!
 - Losing participants (big issue with this population)
 - Forced to use intent-to-treat
 - Identifying an appropriate control
- Pilot-level analysis

Questions?

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