Hope and coping following spinal cord injury

Dr. Pat Dorsett
School of Human Services and Social Work
Griffith University

Session Plan

• The Journey into Hope & SCI

• Two studies
  • 10 year longitudinal qualitative study (Dorsett, P., 2010)
  • Quantitative Hope and Coping study (Dorsett, P., Geraghty, T., Sinnott, A., & Acland, R., 2017)

• Hope Theory

• Hope Enhancing Interventions
My Story

- Social Worker in Brisbane Spinal Injuries Unit late 1980’s - profoundly impacted by the motivating power of hope in my clients.

- Regular referrals to see patients because they were in denial

- Instead met clients who were clinging to hope

- Some concerns that I was encouraging false hope – perhaps detrimental to adjustment???

My Story

- Peer support worker - more than 30 years in a chair
  - “there is never a day that passes that I don’t think about walking”. He added “not that I really think I ever will but I always think about it.”

- Challenged to reflect on what I thought about coping and positive adjustment. And how these were achieved

- Neither my traditional social work education or the prevailing literature

- Reflecting on hope vs denial → Questions and more questions
Questions that needed answers

In light of the prevailing literature and attitudes of rehabilitation staff, is encouraging hope detrimental to long-term adjustment.

If hope was an a positive adaptive response how could one best support hope in clients?

→ Practitioner researcher - learning from the experts – those who had experienced SCI

Background to Hope Theory

1950’s Medical community regarded hope in healing as quackery.

1950’s The beginnings of scientific investigation of hope.

1960’s Emerging research suggesting links between negative emotions & poorer health outcomes. Stage theories of adjustment dominated

1970’s Consideration of the positive alternative view

1980’s Established the links between positive emotions and well-being

1990’s The emergence of the first robust models of hope theory
Qualitative Hope Study (Dorsett, 2010)

- 46 patients consecutively discharged from QSCIS, Brisbane
- 10 Year Longitudinal Mixed Method Cohort Design
- Interviews at discharge, 6 months, 1 year, 2 years, 3 years and 10 years post discharge
- Part of a larger study of adjustment processes which used both quantitative and qualitative methodologies
- The Hope data was only a small component of the overall findings

Significance of Hope

- 70% of the sample clearly identified hope as an essential factor that helped them cope in the early stages following their injury.
- For some hope continued to be important in helping them cope with the long-term consequences of their injuries.
Foci of Hope

Three main foci of hope emerged:

1. Hope for a full and complete recovery
2. Hope for a cure for spinal cord injury
3. Hope for a future life that was satisfying

Hope for Recovery

Hope for recovery is strongest in the early stages post injury but is sometimes maintained even when the respondents admitted that they knew it is a very remote possibility.

“Don’t ever give up. I still think one day I’ll walk again - maybe not the same as before but I still think it will happen. Sometimes I give up but most of the time I think it will happen.” (ID1:6 months)
Sustained Hope

At 6 Months Post-Discharge:
I really appreciated the small things as I began to do things for myself. Being able to turn pages. Being able to get my own cigarettes out of the packet. Seeing things coming back kept me going. The recovery kept giving me hope.” (ID22: 6 month interview).

At 12 Months Post-Discharge:
“I still haven’t come to terms with what has happened to me yet. I’m still counting down for my two years. I know I have to accept it but I am still hopeful.” (ID22: 12 month interview).

Sustained Hope (cont.)

24 Months Post-Discharge:
“I’m still hoping for a full recovery. - I have to keep hoping and keep trying. I have to keep exercising.” (ID22: 24 months).

36 Months Post-Discharge:
“A lot of people need to see that there is a pot of gold at the end of the rainbow- Not just money but good things in life.” (ID22: 36 months).

Note: Change in hope focus from recovery to “the good things” in life, e.g. family and friends
Sustained Hope: 10 Years Post Discharge

But I tried to find out [about a cure], I did go down to the Spinal Unit… One day this year, to find out about like stem cells … that’s been on TV and everything … because I thought if I need, … eggs and everything else like that, well, I thought if I’m coming up to menopause, to get them frozen… (ID22:10 year interview)

Note: Focus of hope has been transferred to hope for a cure.

Sustained Hope: 10 Years (cont.)

10 years Post-Discharge:

“Oh, there’s always light at the end of the tunnel, just at least have a go…and think positive not negative. I know its pretty hard like to sometimes accept but … You’ve still got to fight, you know, life still goes on…Yeah like the Aussie thing, ‘have a go mate!’ ” (ID22: 10 years)

Note: Agency drive the determination to keep working towards goals
Sustained Hope in the Face of Uncertainty

At Discharge:
“|I'm very positive about the future. Positive plus, plus, plus about walking again. It may take some time - like about a year or two but I know I'll get there. I'll be 99% normal again in time.” (ID25: Discharge)

6 Months Post-Discharge:
“|I get very depressed at times especially about walking. I keep asking why did this happen to me? I know it's happened and that I can't turn back the clock. I know that other people are worse off than me. I can't change the past. I have to look to the future but I still get periods of depression." (ID25: 6 Months)

Hope and Uncertainty – 10 years

“I go to the gym like four times a week and plus do a little bit of extra work too but, …the power hasn't come back...I'm more manoeuvrable but it might be ten to fifteen per cent improvement since I spoke to you last, but I'm still severely limited.” (ID25:10 years)
Hope for a Cure

"I have high hopes of a cure. I've been listening to reports about the work being done [overseas]. There is always a doubt but there is always hope to get more movement back. I have plans for the future. I know I'll never be the same as before therefore I need to keep my mind active so I can do well in the future… I want to make as much money as I can so that if a cure does come along I can afford to go overseas for the treatment. I'm pretty hopeful.” (ID33:96).

Hope for Life Satisfaction

“I am working up to a planned future. Even though I don’t have a lot of income I’m still saving. I plan to buy my own home when I’m able to” (ID25: 10 years)

“Just take each day as it comes. I aim to get out on my own with my girlfriend. I'm hoping to get a job too.” (ID2: 36 Months)
More Questions ??????

1. What is hope?

2. Can we identify people with high/low hope?

3. Do people with higher hope cope better, have better long term rehabilitation outcomes following SCI?

4. Can we help people with low hope find hope?

5. What are the implications for staff working with people who have sustained traumatic injury?

So what is this thing we call hope?

- Wishful thinking
- A set beliefs that one’s goals can be achieved in the future.
- An expectation of goal achievement in the future and an action-orientated motivational force related the future.
- An overall perception that in times of threat, goals can be met.
- ‘A perceived future in which the desirable is subjectively assessed to be probable’
- ‘A life force characterized by a confident yet uncertain expectation of achieving a personally significant goal’
- Hope is part of reality negotiation – meaning making – finding purpose
- Hope consists of reality based appraisals of the ‘will’ and the ‘ways’ of achieving goals.
2 Theories of Hope

• Dufault and Martocchio (1985)

• Snyder’s Hope Theory (1991-2006)

Default and Martocchio

• “Hope is a *multidimensional* dynamic life force characterised by a *confident* yet *uncertain* expectation of achieving a future *good* which to the hoping individual is *realistically* possible and *personally significant.*” (Dufault & Martocchio, 1985)

• Hope composed of two spheres
  • Generalized Hope
  • Particularized Hope
Snyder’s Cognitive Conceptualization of Hope

Hope defined as:

“Hopeful thought reflects the belief that one can find pathways to desired goals and become motivated to use those pathways…and serves to drive the emotions and well-being of people” (Snyder, Rand, & Sigmon, 2002)

The Trilogy of Hope

1. Goals – anchor hope – the desired end point of action sequences
2. Pathways – The perception that one can generate workable plans to reach goals
3. Agency – The motivational component which propels people towards goals – includes both thoughts about starting and continuing along a pathway
People With High Hope:

- Are more likely to attain their goals
- Report less severe psychological problems and a more positive outlook concerning problems
- Have more goals for their life
- Preferred difficult goals and complex tasks
- Report greater confidence in their ability to solve problems
- Clearly conceptualise goals
- Are more able to generate alternative pathways when the principle pathway is blocked

(Snyder et al., 1997; Carifo & Rhodes, 2002)

But What About the Question of False Hope or Denial

- Positive illusions, denial, false hope or optimism may act as a buffer which allow people to maintain purpose (Elliot et al 1991; Taylor & Brown 1994; Elliott & Richards, 1999)

- Only at the extreme end of reality distortion is false hope found to be counterproductive (Taylor & Brown, 1994; Elliott & Sherwin, 1997)
More questions???

- Why does one person respond to SCI with hope and others with low hope (hopelessness)?

- Does hope buffer the trauma of SCI reducing the likelihood of depression, powerlessness and despair?

- Research is increasingly indicating that this is the case and that even unrealistic perceptions may assume significance in the coping with stressful or life threatening events.

Hope, coping and psychosocial adjustment

Aim: Explore the impact of hope on coping and adjustment outcomes following SCI.

Design: Longitudinal; Standardized measures, administered at 6 weeks post injury and 3 months post discharge

Hypotheses:

That people with SCI and high hope would:

- have better adjustment outcomes than those with lower hope.
- be more likely to utilise positive coping strategies such as acceptance, fighting spirit, and positive reinterpretation,
- be less likely to use less effective coping strategies such as social reliance or behavioural disengagement.

Sample:

1. Brisbane, Australia
   25 people with newly sustained SCI

2. Christchurch, New Zealand
   22 people with newly sustained SCI

Total Sample = 47

Measures

Hope Measure
• The Snyder Adult Hope Scale

Rehabilitation & Adjustment Outcome Measures
1. The Moorong Self-Efficacy.

2. The Life Situation Questionnaire - 3 subscales:
   » Life satisfaction,
   » Problems of life
   » Self-rated adjustment.

3. The Center of Epidemiological Studies-Depression (CES-D)
Measures (cont.)

• Coping Outcomes

1. The Spinal Cord Lesion-Related Coping Strategies Questionnaire (SCL-CSQ) measures the utilisation of three coping strategies:
   - acceptance
   - fighting spirit
   - social reliance

2. The COPE assesses preferred coping styles as opposed to situation specific coping strategies. We used three subscales:
   - positive reinterpretation (i.e. positive reappraisal, construing a stressful situation in positive terms),
   - behavioural disengagement (i.e. reducing efforts to deal with stressors or giving up) and
   - planning (i.e. thinking about actions strategies to handle a problem).

Australian and NZ Hope Scores

Hope scores: Relatively high for the overall sample at T1 ($M= 26.72, SD= 2.81$); and
Remained consistent over time (T2 $M= 25.91, SD= 3.66$).

Potential Score Range: 8 - 32
### Mean Depression Scores over time

![Graph showing mean depression scores over time for New Zealand and Australia.](chart.png)

- New Zealand: 19.09, 18.45, 19.69, 22.77
- Australia: 18.48, 22.77

<table>
<thead>
<tr>
<th>Time</th>
<th>Mean Depression Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>6-weeks Post-Injury</td>
<td>19.09</td>
</tr>
<tr>
<td>3-months Post-Discharge</td>
<td>18.48</td>
</tr>
</tbody>
</table>

### Coping Styles

<table>
<thead>
<tr>
<th>Coping Style</th>
<th>Time 1 Mean (SD)</th>
<th>Time 2 Mean (SD)</th>
<th>Mann-Whitney U p values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioural Disengagement</td>
<td>5.8 (1.9)</td>
<td>5.3 (1.8)</td>
<td>0.06</td>
</tr>
<tr>
<td>Planning</td>
<td>13.7 (2.6)</td>
<td>13.3 (2.4)</td>
<td>0.55</td>
</tr>
<tr>
<td>Positive Reframing</td>
<td>13.2 (2.8)</td>
<td>12.9 (3.1)</td>
<td>0.42</td>
</tr>
<tr>
<td>Acceptance</td>
<td>12.4 (2.3)</td>
<td>11.8 (2.7)</td>
<td>0.07</td>
</tr>
<tr>
<td>Coping Reliance</td>
<td>9.2 (2.3)</td>
<td>8.7 (2.3)</td>
<td>0.12</td>
</tr>
<tr>
<td>Fighting Spirit</td>
<td>17.5 (2.1)</td>
<td>16.9 (2.2)</td>
<td>0.18</td>
</tr>
</tbody>
</table>

SD = Standard Deviation.
### Spearman’s Correlation of Hope Scores with Outcomes

<table>
<thead>
<tr>
<th>Measure</th>
<th>Spearman’s Correlation (r)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Efficacy</td>
<td>.54**</td>
</tr>
<tr>
<td>Life Satisfaction</td>
<td>.60**</td>
</tr>
<tr>
<td>Self-rated Adjustment</td>
<td>.49**</td>
</tr>
<tr>
<td>Depression</td>
<td>-.35*</td>
</tr>
<tr>
<td>Life Problems</td>
<td>-.55**</td>
</tr>
</tbody>
</table>

Note. * denotes p ≤ 0.05; **denotes p ≤ 0.01; *** denotes p ≤ 0.001.

### Hope and Coping Styles

<table>
<thead>
<tr>
<th>Coping style variables</th>
<th>Spearman’s Correlation (r)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fighting Spirit</td>
<td>.52**</td>
</tr>
<tr>
<td>Planning</td>
<td>.45**</td>
</tr>
<tr>
<td>Positive Reframing</td>
<td>.64**</td>
</tr>
<tr>
<td>Acceptance</td>
<td>.60**</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
<td>-.51**</td>
</tr>
<tr>
<td>Social reliance</td>
<td>-.37*</td>
</tr>
</tbody>
</table>

Note. * denotes p ≤ 0.05; **denotes p ≤ 0.01; *** denotes p ≤ 0.001.
Hypotheses 1, 2 and 3 were proved:

People with SCI and high hope:
1. have better adjustment outcomes than those with lower hope.
2. be more likely to utilise other positive coping strategies such as acceptance, fighting spirit, and positive reinterpretation,
3. be less likely to use less effective coping strategies such as social reliance or behavioural disengagement

So what does all this mean for practice?

Step 1 - Goals

• Clarify Goals – Goals must be important to the person
• Multiple goals
• Failures = learning opportunity
• Set time frames can be an important motivator
• Break up larger goals into sub-goals to increase motivation
• Set challenging but achievable goals – not too easy, not too hard
Goals

"The best thing was getting out of bed, and then into a chair and then to physiotherapy. Once I started getting to the gym I knew there was hope. When I was still in bed I didn't want to listen to the other's positive suggestions about what I could achieve.” (ID41: 6 Months).

Step 2: Build Agency or Motivation

• Ensure goals are important to the client
• Consider the level of challenge
• Teach positive self talk
• Use sub-goals to achieve larger or longer term goals
• Encourage individuals to think about alternative paths towards goal completion
• Instil the belief that individuals can initiate and sustain the behaviour and effort for achievement
• Re-goaling – not giving up
• Peer support or role models of success
Example of Agency

48% of participants in the qualitative study discussed the importance of motivation or drive. This was the 2nd most commonly reported cognitive strategy.

• **At Discharge:** "Don't ever give up trying"

• **Six months:** "I can't give up. My determination is my main driving force."

• **Two years post injury:** "Never give up. At least have a go. What have you got to lose? When you stop trying you should be ready for the wooden box."

Positive Self-Talk

“I put my accident in the background and focused on the things I could do. I go where I can go. I don’t dwell on the negative things.”

"Best way to come to terms with something like this is to treat it like another challenge in life. That's how I felt about it right from the start."
Step 3: Pathways

- Pathway thinking = a usable pathway or plan to get from point A to point B.
- High hope people have clearly specified pathways and are able to modify them if necessary.
- Low hope people have less thought out routes with little ability to find alternative routes
- The rehabilitation practitioner becomes a resource – sharing specialist knowledge with the client to plan pathways to reach goals

Pathways Thinking

"Some days I just make up my mind that I’m going to do something like tying my shoe laces. I thought about it for a while and worked out how I thought I could do it. Then when I had time I tried it. It took most of the morning the first time. I was all hot and frustrated but I did it. Being stubborn helps I think. Now I do it all the time.”
A Final Word - Holistic Approach

• Hope and coping capacity can be challenged in the face of serious and ongoing health and/or environmental difficulties.

• Even the most positive people can lose hope when it seems that the world is stacked against them.

• For example, sustained financial hardship which deprives one of access to necessary resources for independence or community participation can deplete hope and coping capacity. Likewise chronic pain can exhaust hope and coping resources.

• Thus it is important that hope and coping interventions should include holistic approaches which include health, psycho-social and environmental interventions .

• Psychological interventions alone are not able to fully support hope and coping.

Recommendations

Further research to:

• Establish causal links using a larger sample size

• Explore the utility of Snyder’s Hope Model to support hope interventions in rehabilitation settings

• How to cultivate a ‘Culture of Hope’ in rehabilitation settings

• Investigate if there is an inverse coping response in the face of major crises such as natural disasters

• Further research is necessary to more fully explore the utility of this model to support individuals participating in rehabilitation and positive psychosocial adjustment outcomes.
Acknowledgments

Princess Alexandra Hospital Foundation for a grant to support the final stage of the qualitative study

The participants who shared their lives so freely

To the Management and staff of the Queensland Spinal Cord Injuries Service and the Princess Alexandra Hospital Social Work Department

Many thanks for listening