

Exploring the impact of spinal cord injury on partner relationships

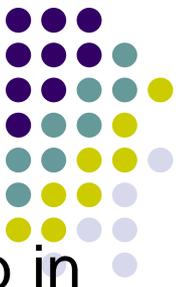


Dr Carol Smyth

London Spinal Cord Injury Centre, RNOH Stanmore

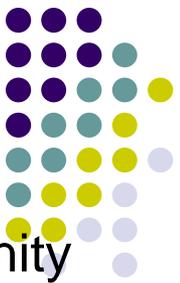
June 2013

Rationale for study



- Aim to explore the experience of SCI on a relationship in order to help advance psychological means of intervention
- Research focus emerged from patient need during placement
- The quality of the relationship post SCI seemed key but no in-depth research
- Much of literature from perspective of partner rather than person with SCI
- Mostly quantitative methods, qualitative analysis recommended
- Most literature focused on adjustment & coping, with impact on relationships not developed

Literature review



- Post SCI, changes in sexual function can affect identity, masculinity & sexual relationship (Burns et al 2007)
- 48% of SCI participants had divorced or separated after injury (Kreuter et al 1998), all participants except 1, divorced/separated after injury (Kennedy et al 2006)
- problems associated when one partner becomes care-giver (resentment, burnout) (Post et al 2005) also changes balance of power, detrimental (Kreuter 2000)
- couples with pre-injury marriage more depressed and less satisfied than those with post-injury marriage (Chan et al 2000)
- stable relationships can impact positively on quality of life in SCI (Hwang et al 2007) and help ameliorate effects of SCI (North 1999)
- Man whose wife rejected him following SCI, more distress than actual injury (Hammell 2004)

Methodology



- Qualitative study
- IPA was chosen in order to gain insight from the perspective of the spinal cord injured person into the support of their partner in the context of a pre-existing relationship. Meaning derived from interpretation of transcripts, carried out according to Smith & Osborn (2008).
- IPA draws on all physical, emotional and cognitive states through communication
- Research question: *how does spinal cord injury impact on partner relationships?*
- 8 semi-structured interviews (6 men & 2 women, 6 tetraplegics and 2 paraplegics), transcribed
- Emergent themes & exploratory comments
- Themes and understandings shared across cases
- 4 super-ordinate themes developed from recurrent themes across whole group
- *Reflexivity*: addressing my interest and possible research bias
- *Validity* – triangulation according to IPA

Process following SCI

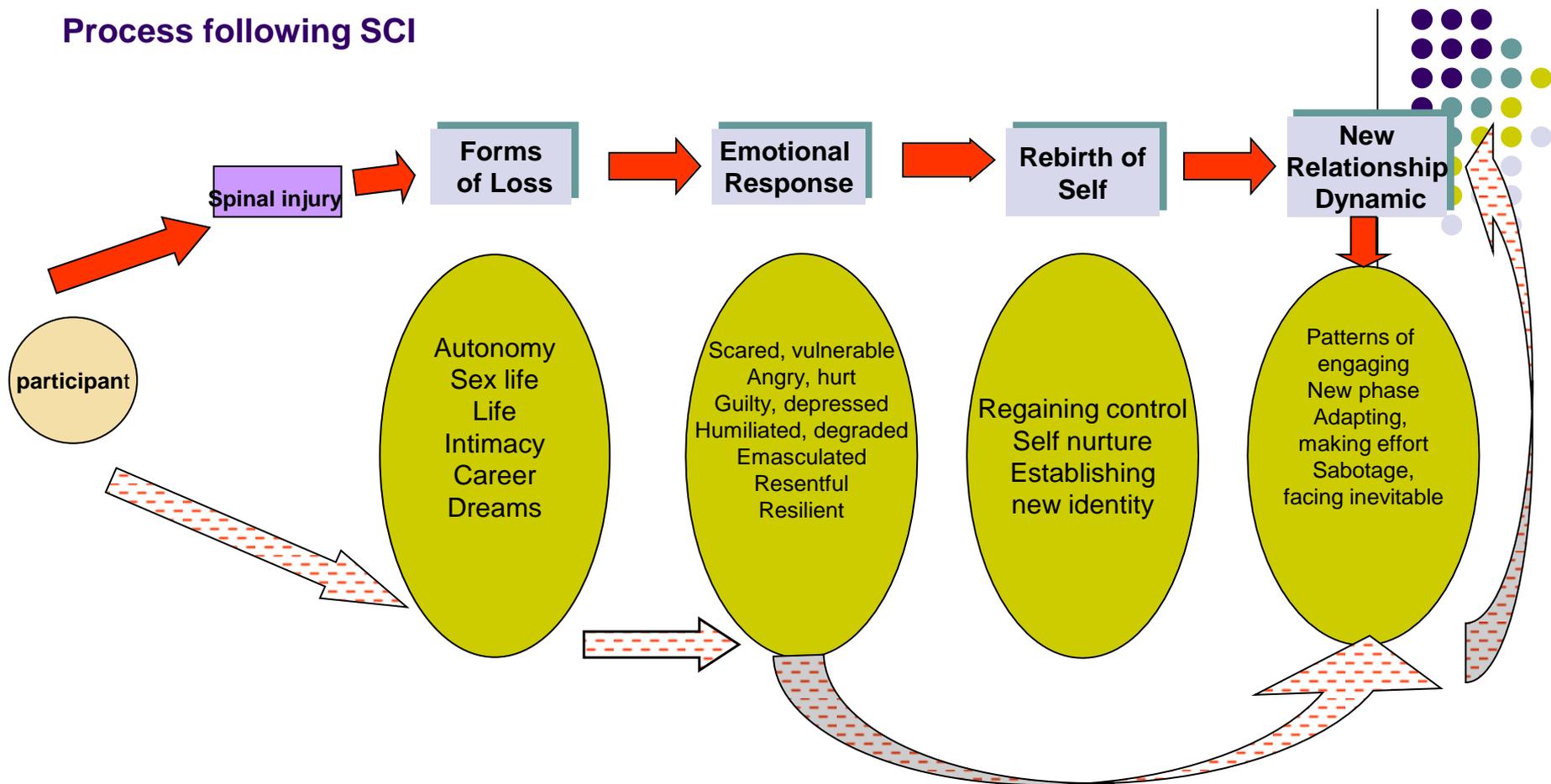
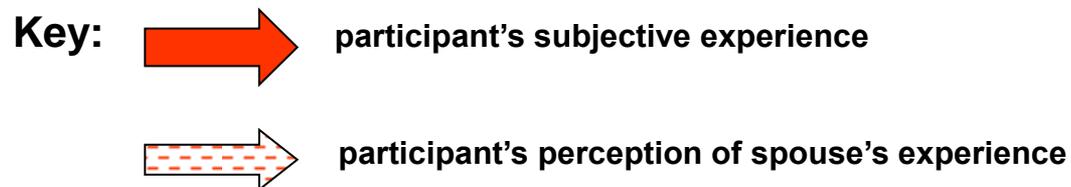


Table 2. Super-ordinate themes, following Spinal Cord Injury of one of partners in a relationship





Analysis

- **Theme 1 – Forms of Loss**

- **Loss of autonomy**

- *Bob: 'one minute fiercely independent to full dependency can't even reach out and grab a book'*

- **Loss of sex life**

- *Colin: 'The sex was a very, very important part of our life prior, and from that angle alone I felt it changed our relationship dramatically. Denise would always just say no no no it doesn't make any difference, but you know deep down that it did'*

- **Loss of life, identity**

- *Jocelyn: 'he liked the feisty me that he'd fallen in love with'*

- **Loss of privacy, intimacy**

- *Dennis: 'that's what sort of gets me the, because we've just not got that where you'd sort of hold her and just sort of stroke her hair and all those things that you can't do any more'*

- **Loss of career**

- *Alison: 'the company moved to different premises and it wasn't at all disabled friendly' 'I do miss what I did before but what I have now is nowhere near as stressful. I have nowhere near the responsibility although I'd go back to it yesterday if I could'*

- **Loss of future, dreams**

- *Dennis: 'I feel the biggest annoyance is because you planned everything, you know you had your kids quite young, you said when you were this sort of age you'd be going round the world and seeing things and going places and stuff like that and that's all been taken away'*

Analysis

- **Theme 2 – Emotional Response**

- **Feeling scared and vulnerable**

- *Jocelyn: 'I became passive and vulnerable. I was so frightened of losing him. I was scared of his temper'*

- **Feeling angry, hurt**

- *Bob: 'My fierce independence had been taken away from me and I couldn't stand the way my socks were being put on so I'd shout at the person doing it 'what the hell are you doing, why don't you do it the sensible way' the way I saw it being the sensible way, plain stupid, and belittling people like that was my sword'*

- **Feeling guilty, depressed**

- *Simon: 'I was blaming myself, I made her put up with a lot. I'm not opposed to her going out unaccompanied so I've got no-one to blame but myself'*

- **Feeling humiliated, degraded**

- *Colin: 'I couldn't wash myself, couldn't toilet myself, I just lay in the bed defecating and peeing everywhere um because they didn't understand themselves how to deal with a para'*

- **Feeling emasculated, ineffective**

- *Joe: 'I don't like to ask her all the time asking to do things having to rely on her but I've got to rely on her' 'I feel different cos I feel useless'*

- **Feeling resentful**

- *Jocelyn: 'he less and less wanted to look after me and more and more resented it, he couldn't cope with the fact that, my legs fell off wheelchairs and I had to ask him to do things'*

- **Feeling resilient**

- *Dennis: 'I've been pretty good, I mean it's the people around me like my wife who's ever so strong and who's helped me through everything'*



Analysis



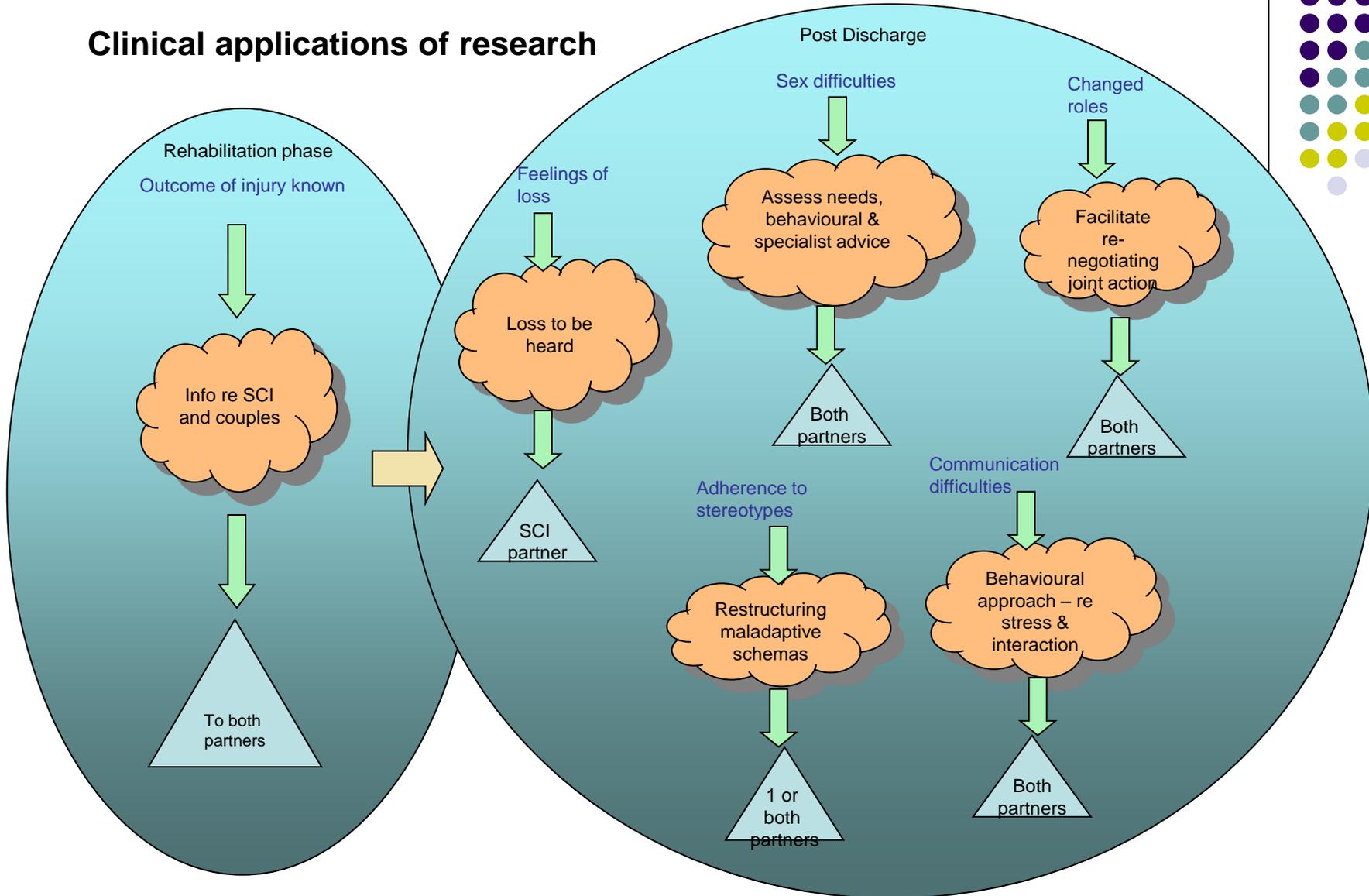
- **Theme 3 – Rebirth of Self**
- **Regaining control**
- *Alison: ‘that’s where the shooting’s good you know I have found something to replace it. If I’m not having a very good day I find it very therapeutic and there are occasions when I just need a session where I can go and just get the lead down the range’*
- **Self nurture**
- *Dennis: ‘I get tremendous joy out of voice activation software, great you know fantastic and a wheelchair that I can operate with my chin, fantastic’*
- **Establishing new identity**
- *Bob: ‘I’m uncle Bob and I chat with my brother’s kids on facebook...maybe there is something I can teach being in a wheelchair’ ‘the man I became, I’m a new person, I’m 11 years old’*

Analysis

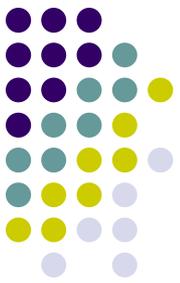


- **Theme 4 – New Relationship Dynamic**
- **Patterns of engaging**
- *Joe: ‘we’ve got the same sense of humour, that’s the biggest thing we’ve got going for us. Keeps us together.’*
- **New phase**
- *Colin: ‘the complete change in the sex life was the most difficult, mentally and physically. It changes everything really from that angle, luckily Denise’s been extremely pragmatic about it’*
- **Adapting, making an effort**
- *Vibran: ‘I’m glad I’m here, fortunately this is not very far from our home it’s on the bus route so it’s easy for Vera to come and visit me’*
- **Sabotage, facing the inevitable**
- *Bob: ‘it was probably the best thing for both of us; for me to live the life I’m condemned to but to do the best I can with it, and for her to go out and get the life that she wanted’*

Clinical applications of research



Preliminary framework of psychological interventions in rehabilitation and post-discharge phases following SCI.



Conclusion

- **Loss of masculinity in men and effectiveness in women significant impact - personally and relationship in some cases too difficult for relationship to survive. Where remained together issue was made more tolerable with support of partner**
- **Also significant - linking of the changes in person following 'biographical disruption' of their life and direct impact on relationship in that partner no longer recognised them**