

Patient's experiences of being discharged home following a diagnosis of malignant spinal cord compression

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Background

- Metastatic spinal cord compression (MSCC)
 - metastatic or direct spread to the vertebrae
- Feature of advanced cancer
 - the incidence is likely to increase alongside improved cancer survival rates
- Consequences
 - Physical effects
 - poor prognosis

Main treatments

- usually palliative in intent

Guidelines and previous research

- The National Cancer Action Team (NCAT) rehab pathway for MSCC (2011)
 - rehabilitation should continue after discharge from hospital
- Review of literature (Harris 2016)
 - experiences of being newly diagnosed with MSCC (Warnock and Tod 2103)
 - Longitudinal exploration of adaptation over time (Eva and Lord 2009)
- Our study: Experiences in the days and weeks following discharge home

Design and methods

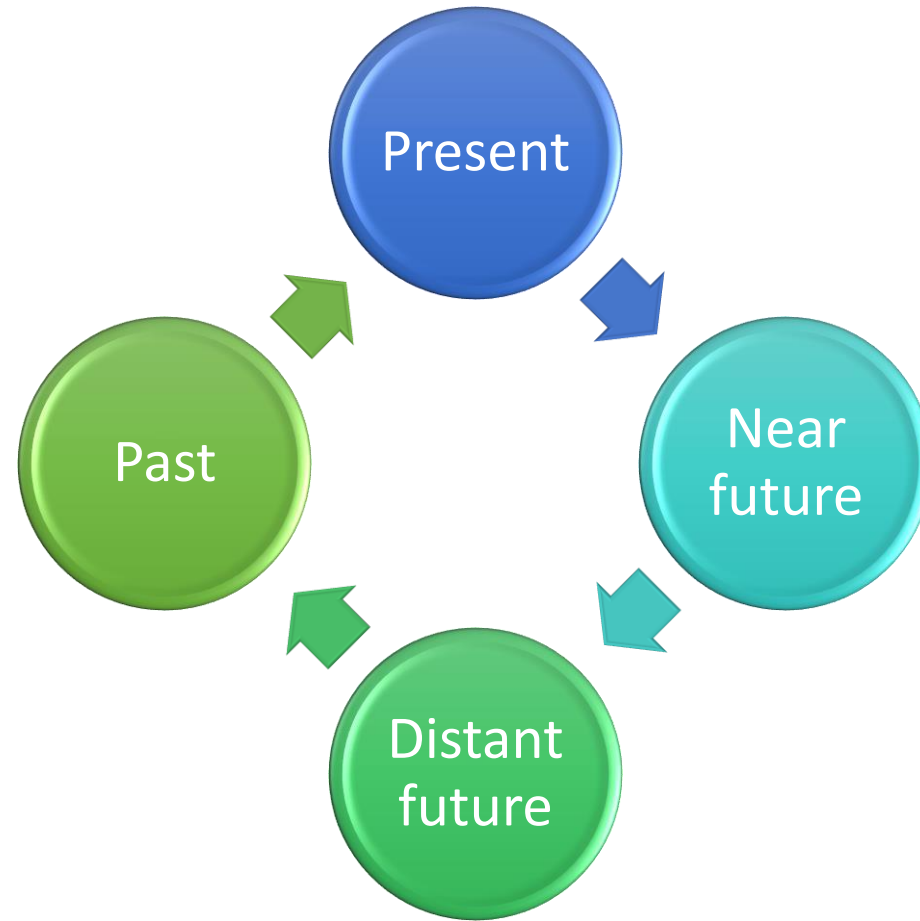
- **Design**

- Semi-structured interviews over the phone (August 2015 and March 2016)
 - newly diagnosed MSCC
 - radiotherapy treatment
 - discharged home from the cancer centre
 - able to communicate in English over the telephone.
- Two time points
- Analysed using Framework Analysis techniques

Results

- During the nine month data collection period
 - 32 admitted
 - 18 transferred to local facilities
 - 14 discharged home
 - 11 in first interview , 10 in second interview
- 10 of the 11 participants were identified by therapy assessment as **independent or independent with walking aid**

Context for participants



Past

- What I used to be able to do
- What used to happen
- Sadness and loss:
 - previously valued activities
 - spontaneity
- Who I was/who we were:
 - our strengths will help us through

“It is quite difficult but we’re coping. You know we’re strong people. We’re just carrying on as normal really.” 018 interview 2

Present

- Getting home

“I’ve got everything I need here. I mean I’m sat in a lovely house with my two lovely dogs and my lovely wife.” – 005 interview 1

- Challenges

- Symptoms

- Limitations

- Personal activities of living, mobility

Challenges

“The only thing I have trouble with is washing. I can’t get a proper wash. I’m washing off a bowl, but getting a shave and doing my teeth, it’s a real pain. Because (wife) gets me the stuff but it’s not easy. It’s not as easy as being at the washbasin”. – 001 interview 1

“Because I’ve no confidence in walking, I just felt as though I were going to fall over all the time. But I feel a little bit more secure now with the walking stick.....But it’s just taking a little bit of effort even just to get out of the house to try walking about”. – 010 interview 2

Present

- Problems not anticipated
- Difference between hospital and home
 - Equipment
 - Nurses
 - Layout
 - Confidence

*“you know you can lower the bed and higher the bed (in hospital) and it was easier. I’ve got quite a big mattress on my bed and probably it’s a bit high”
003 interview 1*

- Support and services at home
 - Variable

Present

- Support from community services - extremely variable
 - *Well as far as the GPs are concerned, I mean it's a complete non-event. I mean they don't, there's no contact whatsoever, even a phone call from the surgery, from the GP or even one of the nurses or something who could ring up – 006 interview 1*
 - *I think if he got a bit of physio, it would help. You know, if they could try and just give him a few things. I mean in hospital they did give him a few exercises to do, but I don't think it's enough. I think we need somebody to have him stood on his legs to see what's what with it. – 004 interview 1*

Present

- Community palliative care nurses seemed to play multiple roles

“Well, I had the Macmillan nurse come to see me yesterday... a lovely lady. She sorted three or four things out.... She’s going to get me one of these lift-up chairs because my ankles are swelling a bit... She’s sorting, possibly, acupuncture, and she’s going to sort physios and OT as well, so she’s on the ball.”

-003 interview 1



Near future

- What I want to do before long
- What will happen soon?

- Short term goals
 - “Back to normal” (modified)

- In limbo
 - Unknown progress and outcomes
 - Waiting for help and services

Distant future

- Long term goals
 - Flexible and adapting
- Thoughts and feelings about the future
 - Cancer outcomes
 - Function
- Living with uncertainty

Living with uncertainty

“Well I mean at the end of the day I’ve got cancer that’s spreading ain’t I?... I mean obviously it’s a big concern, because they never know what it’s going to attack next. But I’m trying to put that at the back of me mind and just carry on with life”. -010 interview 1

*“Yeah, he’s concerned about whether or not he’s going to manage to get on his legs again, more than anything. You know, Dr (oncologist) said he could, or he may not. But nobody can answer these questions at all. It’s just something that’s just got to be, we’ll take it as it comes, you know”.
-004 interview 2*

Bridging past, present and future

TIME			
<p>Past</p> <ul style="list-style-type: none"> - What I used to be able to do - What used to happen • Sadness and loss: previously valued activities, spontaneity • Who I was/who we were: our strengths will help us through 	<p>Present</p> <ul style="list-style-type: none"> What I can do now What happens now • Getting home • Challenges faced at home • Community services: variation in provision 	<p>Near Future</p> <ul style="list-style-type: none"> What I want to do soon What will happen soon? • Getting back to normal: routines, household tasks, personal ADLs • In Limbo: waiting for services, waiting for appointments 	<p>Distant Future</p> <ul style="list-style-type: none"> - What I want to do eventually - What will happen eventually? • Uncertainty: mobility, independence, cancer outcomes • Setting long term goals: flexible and adjustable
<p>COPING STRATEGIES: “one step at a time”, “wait and see”, revising downwards, changing goals, maintaining hope, reframing uncertainty, being positive, being strong</p>			

Variation in experiences

“The Macmillan nurses have been great. They’ve arranged lots of things for me. As I say, I’m going for acupuncture today. I’ve had the OT. They’ve been and they’ve arranged for a bed lift and a step for getting in and out of the shower.” – 007 interview 2

“Yeah I think they (OT) were going to try and get round, but nobody’s been as yet. That were two or three weeks back as regards like such as when I’m getting in bath or shower, I felt very insecure thinking I were going to fall down and one thing and another.” -023 interview 2

Key point 1: unanticipated problems

- Functional problems can be hidden and not recognised in hospital
 - “looking at things in a positive way” – underestimating challenges
 - Impact realised in the home environment
- Patients WANT to get home – priority goal
- Area for future research
 - Usefulness of in-patient rehabilitation
 - patient’s view on the balance between being at home against potential improvements from in-patient rehabilitation

Key point 2: Services in the community

- Services are needed to support transition
- Positive role of a co-ordinator with multiple roles
- Macmillan UK new nursing roles providing one-to-one support
 - met previously unidentified needs, improved access to care and services and addressed concerns
- Area for further research
 - Role and value of specialist practitioners with responsibility for providing and co-coordinating care

Key point 3: Supporting adjustment

- Past abilities and strengths, present challenges future goals
- A range of strategies managed the gaps
 - Flexible and evolving
- Similarities in previous research (Warnock & Tod 2014, Eva 2009)
- Area for further research: what interventions and approaches are helpful and how can we teach and support staff in using them

Conclusion

