Recovery from hip fracture: carer experience

Dr Liz Tutton, Senior Research Fellow RCN Research Institute, WMS, Warwick University, Trauma Research, John Radcliffe Hospital, Oxford

Dr Lorena Saletti-Cuesta, Debbie Langstaff (Matron), Prof Keith Willett





Oxford University Hospitals



- Saletti-Cuesta, L. Tutton, E. Langstaff, D. Willett, K. (2016) Understanding informal carers' experiences of caring for older people with a hip fracture: a systematic review of qualitative studies. *Disability and Rehabilitation*. http://www.tandfonline.com/doi/full/10.1080/09638 288.2016.1262467
- Saletti-Cuesta, L. Tutton, E. Langstaff, D. Willett, K. (2016) Understanding patient and relative/carer experience of hip fracture in acute care: a qualitative protocol. *International Journal of Orthopaedic and Trauma Nursing.* http://dx.doi.org/10.1016/j.ijotn.2016.09.002

Informal Carers

- Hip fracture
 - devastating long term consequences, disability, deterioration walking ability, higher risk morbidity & mortality, high cost (BOA 2007) Hutchings et al. (2011) outcomes of recovery 3-12 months, Griffiths et al. (2015) integration of ageing and hip fracture
- Carer burden is high
 - negative consequences Carretero et al. (2009), Erlingsson et al. (2012)

Meta-ethnography

- PRISMA 3986 articles, 3274 screened, 68 full text articles were assessed, 21 included, 318 caregivers, 67% women
 - 8 grounded theory, 6 ethnography, 2 phenomenology, 5 unclear
 - Quality assessment CASP relationship researcher to participant
- Noblit & Hare (1988) 1-2 getting started/focus of interest; 3 read and rereading; 4 relatedness; 5 translation of studies into each other; 6 synthesis and line of argument; 7 expressing synthesis

Engaging in care: 'struggling through'



Helping others to live

- Maintaining relationships
 - "He is my father-in-law. It's my responsibility to take good care of him. After all, our parents took care of us in the same way when we were young. Now he needs help, it's time for us to take care of him in return" (Li & Shyu, 2007, p.276).
 - "You know it will be your fault if you didn't ask those questions and deal with that" (Macleod et al. 2005, p.1121).
 - "It's a real gift that we have this time together" (p.162)..."She is still my mom and I don't know what I 'll do without her" (Shawler et al. 2004, p.164).
 - "He has become sort of like the child and I'm the parent" (Bryne et al. 2011, p.1380).

Helping others to live

- Providing support
 - "She has difficulty getting onto her legs to use the commode, or whatever, her knickers and petticoat have been soiled. There's been getting clothes to her and making sure they are okay. She's very particular about her appearance" (MacLeod et al. 2005, p.1121).
 - "...we probably have one of the best healthcare systems in the world but it's cracking at the seams and you can see it. If this experience taught me anything it was that our healthcare system is in jeopardy now" (Elliot et al. 2014, p.7).

Adapting ways of living

- Living with stress
 - "Very stressful...it was just trying to juggle everything. You know, work, making sure things were taken care of with his household, my household, visiting him every day" (Nahm et al. 2010, p.5).
 - "Well, it couldn't have come at a worse time to be honest. I have a terminally ill husband and I have a daughter who has just had a caesarean birth" (MacLeod et al. 2005, p.1119).

Adapting ways of living

- Learning through experience intrinsic, interpersonal and environmental
 - "Because I have medical knowledge and experience I could fill in the gaps and ask questions for answers I needed to know" (Giosa et al. 2014, p.143).
 - "It's maturing me. It changed my world view...with aging relatives you see what's going to happen to you and what you have to plan for" (Luptak, 2006, p.34).

Adapting ways of living

• Changing needs over time

- "I feel drained of energy every time she gets worse. Because I feel that she wants me to come every day but I have so much to do at work and the house (purchase) so sometimes I feel that I cannot stand it when she tells me that she is worse" (Elliot et al. 2014, p.455).
- "But it's just to try and get some predictability in my routine, to know what, what's happening" (Byrne et al. 2011, p.1381).

Negotiating the unknown

• Wanting to be involved

- "I was told kind of after the fact but I wasn't included in the discussions ahead of time even though I requested to be included in all of the discussions" (Giosa et al. 2014, p.144).
- Not knowing
 - "My mom and us had no idea as to what was happening, what was being done, what was going to happen, etc. This was a totally new experience and unknown" (Rydholm Hedman et al. 2011, p.6).
 - "So they said something about me making the transfer into the car and I said 'well I am not going to do that I don't know how to do that..." (Toscan et al. 2012, p.6)

Negotiating the unknown

- Being proactive
 - "I mean it's extremely frustrating to try and find somebody who actually knows what the situation is" (Glenny et al. 2007, p.7).
 - "We were pulling it (looking for information) on our own because otherwise it was just a black hole... you are kind of thirsting for information that whole time" (Giosa et al. 2014, p.144).

Engaging in care: 'struggling through

- Is an intense and all-consuming process of helping others to live, adapting ways of living whilst negotiating the unknown which includes a sense of not being valued within the healthcare system
- Challenging emotional, social and physical work that is actively required
- Struggle to be involved, feel valued and gain the information required in busy complex health environments
- Predominant style of learning is through experience

Implications for Practice

- Including them in the umbrella of care within a family centered approach
- Involving them in decisions about care and rehabilitation goals
- Utilising forms of experiential learning to increase their skills
- Providing opportunities for them to explore ways of sustaining their own health through self compassion

Recovery from hip fracture: carer experience

liz.tutton@warwick.ac.uk liz.tutton@ouh.nhs.uk