



# Recovery from cardiac arrest

## Patient's experiences

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# Recovery from cardiac arrest

- What does 'survival' mean?
- Who measures survival?
- How do we measure survival?

# Recovery from cardiac arrest

## What do we know?

- 'Survival' to discharge
  - in-hospital cardiac arrest ~17% (Gwinnutt, 2000)
  - Pre-hospital cardiac arrest 7.6% (Sasson, et al, 2010)
- Range of difficulties experienced by some survivors
  - Post Traumatic Stress Disorder (Gamper et al, 2004)
  - Cognitive, functional and behavioural impairment (Raina et al, 2008)
  - Increased risk of dying in the first year... (Kalbag et al, 2006)
  - Affects their daily lives an that of their carers (Lundgren-Nilsson et al, 2005)

# Recovery from cardiac arrest

- Two recent systematic reviews looking at neurological impairment / recovery
  - Moulaert et al, (2009), 286 papers
  - Trzeciak et al, (2009), 33 papers
- Heterogeneity
  - outcome measures
  - study design
- Neurological outcome presented simply as ‘good’ or ‘bad’

# Recovery from cardiac arrest

- One very recent systematic review looking at Quality of Life
  - Elliott et al, (2011) Resuscitation 82, 247–256
  - 70 papers from >5000
- Highly Heterogenic
  - Study design
  - Outcome measures
  - Neurological outcome

# Recovery from cardiac arrest

- 47 'good QoL'
- 17 'neutral QoL'
- 7 'poor QoL'
- 65 different neurological 'tests' used across 70 papers
  - CPC used in 20%
  - Use of 'validated' and 'simple' tests
    - HADS / SF-36 / MMSE / <5%
- **“There is a requirement for consensus development with regard to quality of life and patient centred outcome assessment in this population”.**

# Recovery from cardiac arrest

- What did any of this 'evidence' tell us?
- Isn't this all just a medical perspective of recovery from cardiac arrest?
- What do we actually know of the patient's experience?
- No appreciation of 'biographical disruption' (Bury, 1982)

# A Research Journey...

- 1993, St George's Hospital, London.
- 1998, University of Liverpool, Fenwick telephone by a young SHO



Fenwick



- Enrolled professional doctorate

# The AWARE Study

- Semi-structured interviews
- Greyson score used to validate a positive result
- What the patients revealed to me provided the inspiration to undertake my doctoral research...



# Recovery from cardiac arrest

- Two 'qualitative' papers, both pre-hospital
- Lau et al, (2010)
  - 9 patients, semi-structured, telephone interview, 1-11 years post discharge.
  - Targetted 4 'key themes'
    - Patient & family perception of medical prognostication
    - Patient's definition of death
    - Use of advanced directives
    - Perceptions of health & organ donation

# Recovery from cardiac arrest

- Findings
  - Difficulties and inaccuracies re prognostication
  - Challenging range of responses re patient's definition of death
  - Use of advanced directives – rarely if ever discussed
  - Most considered that they were healthy and few considered organ donation

# Recovery from cardiac arrest

- Bremer, Dahlberg and Sandman (2009)
  - 9 patients, all 'cardiac', >6 months post discharge.
- Summary Findings
  - Unexpected serious life threat and elusiveness
  - Loss of memory recall, disorientation, vulnerability
  - Search for coherence and the limitations of life
  - Gratitude, well-being and re-assertions regarding the sanctity of life

# What patient's said...

- “I didn't know that these things could happen, it was . . . beyond my ordinary world.”
- I don't know if one understood that it was . . . that it was something that could be life threatening or so. . . . I don't believe . . . that I, I don't know what I thought but . . . I suppose that I thought, truly it can't be possible that this could be . . . the end, already at this age.

# What patient's said...

“What have I done? Where am I? Where is Rose? I remember them . . . on the third so to speak. How is she? Who else are, so to speak, in this . . . chaos, er? How did I get out of here?”

“So then I more like stepped into this everyday again.

“What is going to happen now . . . ahead? How sick will I become after this? What am I allowed to do later on?...

# Recovery from cardiac arrest

- Summary Findings
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Search...

Search

See all conditions

Cancer

Nerves & brain

Mental health

Dying & bereavement

Chronic health issues

Intensive care

Heart disease

Bones & joints

Pregnancy & children

Carers

Autism

Medical research

Later life

Young people

Women's health

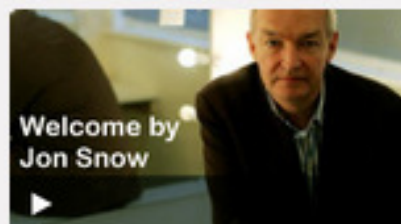
**“True stories are...nutritious and sustaining.  
They feed the mind with information and  
the heart with hope and strength..”**

Philip Pullman

People's stories: see, hear and  
read their experiences...

Healthtalkonline is the award-winning  
website of the DIPEX charity and  
replaces the website formerly at  
dipex.org. Healthtalkonline lets you  
share in more than 2,000 people's  
experiences of health and illness.  
You can watch or listen to videos of  
the interviews, read about people's  
experiences and find reliable  
information about conditions,  
treatment choices and support.

The information on Healthtalkonline  
is based on qualitative research into  
patient experiences, led by experts  
at the University of Oxford. These  
personal stories of health and



An introduction to  
healthtalkonline.org



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“ in the news ”

Women's  
health



# Waking up in ICU...

“I was trying to piece things together in my mind. I was trying to put right a jigsaw of my life, if that's the best way to describe it. And I needed to put pieces together to complete, as I was before. I know it's going to be a question of time but my life was built like a jigsaw. Several pieces fit into place and then your life becomes part of a big scheme again”.

[www.healthtalkonline.org](http://www.healthtalkonline.org)

# Recovery from heart attack...

“I think literally when I came out of hospital first time, that was such a common thing. I mean, I'd go straight to bed if I was feeling alright, just a bit uncomfortable. But if there was a bit more than just uncomfortable, I shut my eyes, I'm never going to wake up, so what I'll do is I won't shut my eyes, and I know it's absurd, but it's a fear that's engendered within you and I try to put it to people in the sense, it's not the intensity or lack of the pain, it's the source of the pain that's the worry”.

[www.healthtalkonline.org](http://www.healthtalkonline.org)

# Biographical disruption...

“I started to go back (to work) after six weeks on two days a week short hours, three days a week short, then three days a week longer hours. I think, I reckoned it must, that, we did that over about twelve weeks and then I was back at work”.

“I was quite angry at first that I'd had to give up. It was a decision that was made for me and I really was quite upset that I had to stop before what I thought was the time I should.

# Other qualitative work

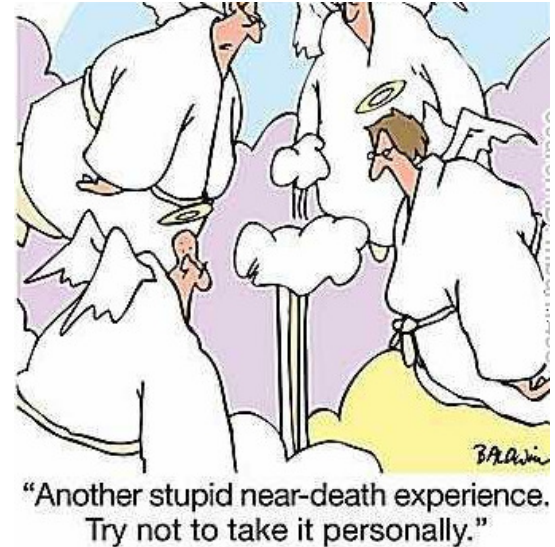
- Real recovery experiences of ICU patients (Prinjha et al, 2009)
- Recovery from myocardial infarction
  - (Wiles, 1998)
- Recovery from implantable cardioverter/defibrillators
  - (Kamphuis et al, 2004)

No studies considered

- in-hospital cardiac arrest
- the acute phase of recovery...

# What do I want to know?

- Thoughts and perceptions
- Fears, worries & concerns
- Biographical disruption
- Recovery
- And anything else that patients want to say...





**Thank you for your kind attention**