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COLLEGE OF MEDICINE & DENTISTRY
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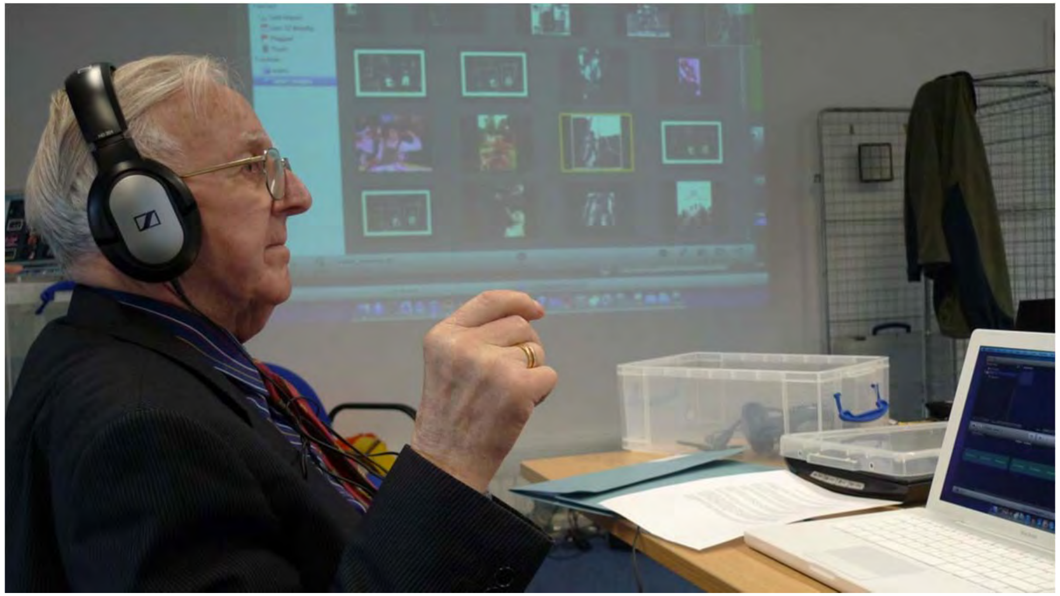
The NIHR CLAHRC for the South West Peninsula

Past Caring: A carer-led, narrative research project about carer bereavement

Project Summary: Aug 2010 -Mar 2012



digistories
digital storytelling

What was the Past Caring Project and who did it?

The Past Caring Project collected stories of people who have spent time caring for a person who has died or is lost to dementia. The project was about what comes next, how we feel and what we experience. The project took a group of 8 bereaved carers through two sets of intensive four-day courses where we each made a digistory or short film. We also did an extended interview about our experience of caring and of losing the cared for person. We spent a year working together to gather these interviews, analyse and examine what we found and training and support was provided. We had counselling support for everyone who wanted it. So the design was participatory and emancipatory –the project was originated and managed by carers, with carer involvement at every stage.

Background -Why did we do a Bereaved Carers Project?

'Carers' provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. There are about 6 million people in the UK that are simply 'getting on with it' and taking a huge strain, some for many years of their lives. Bereaved carers are those who have had a 'cared for' person who has died. Despite the awe which each of us must feel in the face of death, some have suggested it is easier to die than to survive. Services are (if all goes well) mobilised for the dying. For the survivors there is often nothing. There are ordinarily no carers for the carers in their bereavement as there were for the dying. They are on their own. Carer bereavement is barely recognised in public practice.

The Past Caring Project tried to do something about this. Carers got together and did a research project, using digital storytelling and interviewing . We are interested to use the findings to work with service providers and gather support amongst fellow carers to create a platform to bring about change in communities relating to the way bereaved carers are treated and understood. We are also interested to share our experience of doing service user led research.

What were the Past Caring Project Aims?

- ***To fill a gap in carer research***

  This project aimed to contribute to base-line information about the phenomenon of carer bereavement.

- ***To give bereaved carers a voice***

  Jones suggested that *'One of the hardest things in life is having words in your heart that you can't utter.'* To take an interest in bereaved carers stories and to collect, value and pass on these stories will give carers a voice they have not had to date.

- ***To offer carers emotional support***

  To offer full back up support from a trained counselor.

- ***To develop an innovative, multi-method design***

  By moving outside a reliance on written print media, the project sought fresher, more inspirational ways of telling, through sound interviews and digital stories. This makes research more accessible to and more accountable to those who take part and the public more widely.

- ***To influence practitioners and change policy***

  Stories have been shown to offer powerful tools to influence policy agendas. These stories aim to inform a better, more sensitive response by statutory and non-statutory services to the needs of bereaved carers.

- ***To change carer research agendas***

  Research agendas and topics are often set for carers and this project aims to draw on carers own agency in changing the production of useful research. It was about making opportunity and removing barriers to carers doing their own research.

- ***To offer carers high quality training and skills exchange***

  There has been considerable recent attention to engaging older people in improving information technology skills and this project aimed to add to this agenda in a capacity building way. Also to offer on-going support in using research recording and analysis equipment and techniques, and sharing the extensive existing research skills of those involved within the project group.

- ***To directly improve bereaved carers lives***

  Telling stories in supported ways can have important cathartic effects and help to create new 'future stories'.

Who were the Past Caring Project Team?

This project was started by bereaved carers who were Folk.us members, led by Rosemary Whitehurst, Victoria Jones and Brian Ruel. Folk.us helped the group put together a proposal and recruit an expert group of freelancers to support the project, keeping control in the hands of the carers, with technicians putting their knowledge and skills at their disposal.

'Folk.us' is a not-for-profit team that was funded by the National Institute for Health Research (NIHR) and based at the Exeter Medical School /University of Exeter. We supported service user, patient and carer involvement in health and social care research. In direct response to service users ideas, we helped people set up projects and offer them on-going support. We also did training, networking and events to inform our work. We had a membership of 270 members of the public. Rachel Purtell is the Director, Wendy Rickard is the Research Fellow.

Barrie Stephenson helped run the ‘Past Caring’ digital storytelling workshops. We were very lucky to have the opportunity to work with Barrie. Amongst his 18 years of experience working at the BBC as radio producer and managing editor of two BBC local radio stations, he headed up the digital storytelling initiative ‘Telling Lives’. More recently, he conducted a digital story-telling project in partnership with a group of carers and social workers in Kirklees (Carers Gateway in Huddersfield, 2006). Barrie led the team at Radio York that won a Sony Gold Award for it's community service to North Yorkshire during the floods of 2000. Julie Wyman was our project bereavement counsellor. With significant experience of working with carers, Julie was employed to be available on demand throughout the project period.

The project was endorsed by The Princess Royal Trust for Carers, which is a UK-wide network of nearly 150 Carers' Centres, reaching over 350,000 carers. A Carers Social Event was kindly funded by Devon Virtual Carers.

The Participants

- 8 participants – 2 men , 6 women.
- Age range 54-85 years
- Primary caring relationship: Kath (son), Rosemary (Mother), Brian (neighbour) and John, Liz, Susan, Gill and Victoria (wife and husbands respectively).
- Long term caring - Liz was a carer for over 30 years, Kath for 20 years, Susan for 15 years, John for 13 years, Gill for 12 years, Rosemary for 10 Years, Victoria for over 7 years and Brian for 3 years.

Some of our digistories are on You Tube:
www.youtube.com/folkusuk

Findings: 7 Themes.

Here are some example quotes from participants,

showing the kinds of issues that came up in the interviews.

1. Stress

Stress-related problems – 'When you adapt to that sort of level of stress, it's, it's very difficult to let go'.
Breakdowns 'I think it was a sort of awesome responsibility'
Residual Guilt –'Did I do enough?'
Fitness and mortality –'I'm very well aware that tomorrow... I could even be dead'

2. Death Stories

Long death story, short bereavement story-'If I stop, I'm never going to start again… so I must just do something' .
Predictable or unpredictable time of death –'"These are probably your mother's last days", I mean nobody actually said that'.
Place of death – 'He was shunted into a side room and put on a syringe driver and left'
Early bereavement memory loss – 'I suddenly couldn't remember the names of things'

3. Positive Perceptions of Caring

Caring as love –' you're doing what you're doing because *you care*. And it's done *with love'*.
Caring as reward – 'I thought well thanks for letting me into your life, you've helped me'
Caring as return altruism over a lifetime –'She was like a good fairy'.
Positive things in bereavement –' I'd always kept bits of my life going'

4. Social world

Living' bereavement – 'my mother coming to live with me would, would really impact on the way I was going to be able to live my life'.
Pre-bereavement isolation– 'you start to lose people'
Bereavement isolation -I now come home to an empty house... there's nobody there... '

5. Services

Support groups for carers –' how many years since you had bereaved was a valid period (to remain at the group)?'
Crass Remarks from service providers 'the problem is you have the wrong needs'
The carers relations with services – 'I (as carer) had to do all the difficult discussions... I was presented as the awkward person'

6. Caring experience

Being cared for in the family –'how to look after was deeply imprinted'
Good caring -' I felt when she died that I'd done the best I could'.
Serial carer bereavement –'socially isolating... quite, quite grueling'
Parenting bereaved children –' sad to say, I got slightly annoyed with her (my daughter) in the end because she made it worse for me'

7. Money matters

Money issues while a cared for person is alive –'I won't fit the criteria'
Managing Money in early bereavement–'It was incredibly arduous'
Managing money in later bereavement -'we compare notes'
Guidance with finances –'Never alone'
Inheritance issues –'I'm not over here for money'

Reflections on Project Involvement

1. ‘Good... not easy’

It’s felt okay. It’s brought back lots of sad memories. I’ve cried a lot. But it’s all right. Yeah. It’s okay... I think my emotions are really quite near the surface. I do cry easily. But then I do laugh easily, too. (Rosemary)

2. ‘Processing what’s happened’

Every now and again you have to climb one of the tallest trees and look at where you’ve been, and are you still headed in the direction where you want to go? And I think that’s, for me, what, what this is all about. (Kath)

3. ‘It made me feel less unvalued’

I did feel the digi-story was far more about me, whereas other things have been, the focus has been on N (cared for person), and I’ve found that quite uncomfortable, because I’m out of the habit of thinking about me much. But also very good for that reason. (Victoria)

4. ‘It has restored the identity and confidence I lost’

It has restored the identity and confidence I lost when I left work through stress, and enabled me to use skills I thought were lost to me, as well as learning new ones. (Victoria)

5. ‘To share that with people’

As far as the digistories were concerned, there was a very positive effect for myself and my family in watching the story afterwards. (John)

What comes next?

We would like to find funding to extend an invitation to others to record their stories at a decreased cost, as investment in the initial research model development and training have been paid for and we now have an expert team of trained people to undertake further training with their peers in a capacity building model.

We would like to develop the technical aspects of the project (by using IPads) to make it more flexible in terms of the time commitment required of participants, developing a model we can use with groups, individuals and pairs and potentially work with people in their own homes or mobile locations, over less intensive time periods.

We would also like to develop the model in different contexts, particularly in hospices and in other geographical areas of the UK . Any off-shoot projects will continue under the governance and control of service users /carers.

For more information, ring Folk.us on 01392 403049 (Mondays)