
Unheard, invisible, invaluable

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Unheard, invisible, invaluable

Care, n. Solicitude, anxiety; occasion for these; serious attention, heed, caution, pains; charge, protection, etc.

Care, v.i. Feel concern or interest for or about; provide food, attendance, etc., for (children, invalids, etc); (w.neg. expressed or implied) feel regard, deference, affection, for, be concerned whether etc. (often with expletive a pin, a damn, a farthing, a tinker's cuss; couldn't care less, colloq., be utterly indifferent; I don't care if I do, am willing); be willing or wishful to (should not care to be seen with him)

Concise Oxford Dictionary (1964)

Carers provide the vast majority of health and community care in the United Kingdom. The value of the work done by carers is estimated at between £34 billion and £57 billion per year – roughly equivalent to the entire UK budget for health (the NHS budget in 2003/4 was £56 billion).

Who cares?

'I didn't realise I was a carer. I'm her husband and thought it was my duty to look after her.'

This comment, made by a 69 year-old male carer, is typical of many. And yet, according to Kendra Inman (and others) there are six million men and women in Britain whose help allows relatives, partners or friends to live at home. In addition there are between 20,000 and 50,000 young carers, aged under 18, who provide significant amounts of care for a parent or relative.

The Department of Health defines carers as:

'people who look after a relative or friend who needs support because of age, physical or learning disability or illness, including mental illness.'

Approximately one in every ten people in Britain fits this description.

Despite their detailed knowledge of their patients and the conditions that affect them, many carers are excluded from decision-making and not acknowledged as the main care provider.

One woman, after injecting her haemophiliac husband with Factor 8 to stop a bleed, as she had done frequently in 20 years of caring for him, overheard two nurses complaining that she was 'interfering with their care of their patient.' Although perhaps not always voiced, this is doubtless a common feeling among clinicians.

It's not only clinicians who under-value the work of carers. This exchange between a (male) carer and an acquaintance epitomises public perceptions of caring and what it involves.

'What do you do?'

'I'm a carer.'

'But what do you really do?'

'I'm really a carer.'

'Well, what does that involve?'

'I look after an elderly woman.'

'But you must do something else, surely?'

Not only is the work of carers unpaid, but it is considered to be so unimportant as to be almost unbelievable, particularly, it seems when the carer is male.

So the invaluable, yet thankless, work of carers goes unrecognised, and their voices unheard.

'When will our consciences grow so tender that we will act to prevent human misery rather than avenge it?'

Eleanor Roosevelt

Hearing what patients and carers have to say: Patient Voices

Mindful of the NHS promise to give patients and carers 'choice, voice and control', the Clinical Governance Support Team has developed a series of short video clips that place patients firmly at the heart of care. They are proving to be a powerful means of engaging the feelings of Trust Board members, managers, clinicians and others striving to improve the quality of healthcare, and a valuable educational tool in the service of patient safety and quality of care.

Patient Voices are 'digital stories' that use video, audio, text and music to convey patients' own stories in a unique way.

The idea came from our desire to use the power of patients' stories to touch hearts, and not simply engage minds. Digital stories created by Brendan Routledge in his education work with children, referred to as 'Powerpoint for the soul', provided the perfect format for us to put patients firmly at the heart of healthcare.

Paul Stanton, acting Head of the Board Development Team, who commissioned the videos, praises the courage of the individuals involved in talking frankly about their own experience.

'They enable my team, and other staff from the NCGST to give concrete expression to our commitment to put patients' and carers' perspectives at the heart of all of our work with NHS staff.'

Patient Voices reflect the patience of both patients and carers. They:

- redress the balance of power between healthcare clinicians and managers and those they serve
- give decision-makers a new way to see the needs of patients – other than through dry statistics and survey results.

Patient stories are making a significant contribution to understanding the patient experience (Greenhalgh and others); they acknowledge the patient's own areas of expertise, i.e. his or her own life and unique experience of illness.

Research on public perceptions of the NHS (Page, 2004) reveals that patients care much more about being treated with dignity and respect than about mortality rates. If patients are really to be 'at the heart of healthcare', as the Department of Health suggests, then their views and stories are of paramount importance in any reform of health care services.

The Patient Voices stories can:

- highlight gaps in the system
- reveal near-misses
- form 'free learning opportunities'
- promote healing and reconciliation
- allow the voices of patients and carers (and clinicians) to be heard
- carry forward stories that might otherwise be lost (like that of Fred, a man who had aphasia following a stroke).

The stories are:

- created in the spirit of collaboration and partnership
- intended to touch hearts, thereby reasserting the place of patients at the heart of care.

The Patient Voices programme aims to capture some of the unwritten and unspoken stories of ordinary people so that those who devise and implement strategy, as well as clinicians directly involved in care, can work in a more informed and compassionate manner.

We hope that, after making and seeing these stories, patients, carers and clinicians may meet as equals and work respectfully together for the benefit of all.

In recognising, along with the actor, James Earl Jones, that 'one of the hardest things in life is having words in your heart that you can't utter', a thoughtful protocol has been devised to make it as easy as possible for storytellers to tell their stories.

In seeking to uphold the values of respect, dignity, equity and trust, storytellers are given plenty of information about what we would like them to do and what they can expect from us.

Several conversations usually precede the recording session. We discuss the stories they are likely to tell and describe the process. Briefing notes and blank storyboards are provided and any questions are dealt with in a timely manner.

Many people want desperately to share their stories but find it incredibly painful to do so. A trained counsellor is one of two people attending each recording session in case emotional is needed, but most storytellers have commented on the therapeutic, even cathartic, nature of the experience.

We attempt to show the carer how we value their contribution and time. Generally, recordings take place in the storyteller's home but, if travel is desirable, expenses are reimbursed on the day; carers without other income are paid for their time.

Monica Clarke, one of the carers involved in the project, said:

'I was pleased that I had this opportunity to let others hear my experiences. If what I and my colleagues, who also told their stories, had to say helps improve how other people in our position are treated, then it will all have been worthwhile.'

Interest in the use of digital stories in healthcare education is not restricted to the NCGST. In the USA, the Patient Voices videos won two awards at the 2004 Dartmouth Clinical Microsystem Film Festival, including the People's Choice, (Paul Batalden) Award for the best overall entry in the festival.

Paul Barach, Medical Director of Quality and Safety at Jackson Memorial Hospital and Associate Dean of University of Miami Medical School, commented:

'These remarkable short vignettes are the most powerful stories I have seen on these topics. Elegant, short and yet they deliver a real punch. I believe they could be very useful as an educational tool for medical students, registrars and faculty. They might help to ensure greater patient safety awareness as well as going some way towards improving the quality of the patient experience. They might also assist in providing encouragement to people dealing with long-term conditions.'

The videos will also be presented at the Clinical Microsystems European Festival in March, 2005.

Making the invisible visible: engaging carers

'Culture of the mind must be subservient to the heart.'

Mahatma Gandhi

Carers can best be empowered if we acknowledge:

- their existence
- their vast knowledge of those they care for and the range of conditions affecting them.

Health professionals need to listen to and respect carers' experience and expertise, and carers need to have the confidence to speak up and be heard.

Clinical Governance aims to assure the safety and quality of care and to transform existing models and patterns of care in order to realise the values of equity, respect, humanity, and trust.

The *Heart of Care* project has been set up by the CGST in collaboration with Pilgrim Projects, with the intention of producing a series of publications placing patients and carers firmly at the heart of health care. It also seeks to explore the possibilities (indeed the necessity) of true collaborative partnership and genuine respect for and use of patients' and carers' expertise and commitment, especially in the management of chronic ill health.

The first priority for The Heart of Care programme was 'the invisible army' of carers. Discussions with The Princess Royal Trust for Carers led ultimately to a one-day workshop for carers, clinicians and managers to promote working in partnership with carers and to ensure that carers' voices are heard throughout the publication(s).

The structure of the Engaging Carers workshop was based around three questions:

- 1 What are the benefits of engaging carers as full and active partners in care?
- 2 What are the obstacles that prevent this kind of engagement?
- 3 What factors promote engagement?

As Paulo Freire commented:

'dialogue is the encounter between men, mediated by the world, in order to name the world.'

This day presented an opportunity for carers to speak and be heard: to engage in a genuine dialogue with representatives from various levels of the health service to share experiences and exchange opinions in a safe, supportive and contained atmosphere.

We viewed the workshop as one episode in a journey towards better care, not unlike Dewey's (1938) notion of learning as a continuous process:

'the principle of continuity of experience means that every experience both takes up something from those which have gone before and modifies in some way the quality of those which come after ...'

Mindful of the values of clinical governance, which lie at the heart of all our work, and of the need to provide an appropriate environment for the kind of reflective and reflexive learning that we hoped would occur during and after the day, considerable thought was given to arranging every aspect of the day.

Great care was taken to ensure that participants felt comfortable and at ease both emotionally and physically. It seems that we were successful in our aims. Feedback from all participants was enormously positive, with many declaring the workshop the best they had ever attended.

Perhaps part of our success lay in our determination to listen, and to hear, what was said (and in some cases, what cannot be said). Hans-Georg Gadamer (1979), an educationalist, proposed that:

'[Conversation] is a process of two people understanding each other. Thus it is a characteristic of every true conversation that each opens himself to the other person, truly accepts his point of view as worthy of consideration and gets inside the other to such an extent that he understands not a particular individual, but what he says. The thing that has to be grasped is the objective rightness or otherwise of his opinion, so that they can agree with each other on a subject.'

While we might disagree about the intrinsic rightness or wrongness of an opinion, the need for a genuine commitment to listen in order to hear and understand and expand what Gadamer calls 'the horizon of understanding' was fundamental to planning the day.

On the advice of Monica Clarke, the Patient Experience representative, we were determined to provide an opportunity for carers simply to meet and talk to each other and, importantly, to provide a safe space in which to deal with the feelings of anger and frustration with which most carers are, sadly, familiar.

Thus, after the introductory session, we spent 20 minutes during which everyone in the room identified first, a feeling they had experienced on a bad day of caring for someone and, second, a good quality they recognised in themselves in the ongoing task of care. By the end of this session, mutual trust had been established. By lunchtime, participants were so engrossed that no-one left their tables until the third announcement that lunch was served!

Such meticulous attention to practical details ensured that the learning experience was a holistic one; experienced through the mind, the body and the heart. Our somewhat grandiose aim was to emulate Waterhouse's

'continuously supportive process which stimulates and empowers individuals to acquire all the knowledge, values, skills and understanding they will require throughout their lifetimes and to apply them with confidence, creativity and enjoyment in all roles, circumstances and environments'

(Waterhouse, 1996)

The energy and goodwill engendered by the day were heart-warming and incredible, as was the gratitude of the participants for things that seemed simply human or, at least courteous.

If what happened during our carers' day was remarkable, then the qualities that we might expect in an activity as universal as healthcare, such as compassion, respect and justice, must be in remarkably short supply.

If a genuine passion for collaboration and a desire to improve the lives of carers and patients can engender so much goodwill, then there is hope for all of us who experience the health service, whether as patients, carers or 'professionals'.

This is the stuff that social change is made of.

The facilitators also declared the day a success. Monica Clarke hails the day, its organisation and what has resulted from it, as:

'a new way of collaborative working – from the heart – a way of working for the future.'

However, the emphasis on the importance of process must be balanced against the need for genuine outcomes that improve carers' lives.

These words from a carer (who did not attend the workshop) carry a powerful message that we must continue to move forward and resist any temptation to view the process as more important than the outcomes.

'In my experience, within weeks, if not days, the good feelings generated by a successful conference dissipate, unless the carers see for themselves a significant attitude change, and that is where I for one would like to see the focus. At the very most, the good feelings give enough pep to an already exhausted person to go home and start battling against the odds again. But it can't last because the carer is already exhausted.'

Carer of an adult daughter with learning disabilities
There are no easy answers, only what Brenda Zimmerman (2004) calls 'wicked questions': those with no set answers but with an inherent paradox or tension embedded in them.

Bringing such questions into awareness helps to expose underlying assumptions by opening up options and lines of inquiry and raising the fundamental issues that need to be addressed.

Where do we go from here?

Speaking about mobilising for social change, Helen Bevan (2004) of the Modernisation Agency reminded us of Antoine de St Exupery's wise words from *The Little Prince*:

'If you want to build a ship do not gather men together and assign tasks. Instead teach them the longing for the wide endless sea.'

We have reviewed our ideas about the book we will write. We originally intended to summarise the discussions arising from the three questions, and make some recommendations.

Our thinking now is to write about the process and what we have learned from it, in the hope of inspiring in others the passion and compassion that contributed to a unique experience.

We hope to describe this experience, and the factors that created it, with contributions from those involved and to derive some broader lessons that could be useful to many people in the NHS. We want to:

- cultivate compassion, understanding and respect
- take care in all that we do
- listen deeply and carefully to others (particularly to patients and their carers)
- be flexible and responsive
- acknowledge (and celebrate) the multiplicity of skills and talents that make such an event work
- maintain an open and honest dialogue
- ensure that the voices of everyone involved in caring for patients are heard
- *'be the change we want to see'* (Mahatma Gandhi).

Such a publication might not be unique but will, I believe, help to shift the focus from product and outcome to process and the real source of change, bringing to mind the words of Derek Mahon:

'The hidden source is the watchful heart'.

In our attempts to bring about social change, we awaken a new understanding and come to a new awareness of what really matters. As Michael Jones (2004) says:

'Beauty and the sense of belonging it evokes introduces us to a new standard of care--a quality of attending-- which we may extend to our sense of stewardship in creating communities of care. Perhaps in the future a well lived life will involve the shift from a focus on utility to the combined search for signs of the beautiful.'

Perhaps this is where transformation begins.

Everything is going to be all right

Why should I not be glad

To contemplate the clouds clearing beyond the dormer window

And a high tide reflecting on the ceiling

There will be dying,

There will be crying, but there is no need to go into that

The poems will flow from the heart unbidden

And the hidden source is the watchful heart

The sun will rise despite everything

And the far cities are beautiful and bright

I lie here in a riot of sunlight watching the daybreak and the clouds flying

Everything is going to be all right.

Derek Mahon

References

- Bevan, H. (2004) 'Mobilising for Social Change'. Presentation at Modernisation Agency's Past, Present and Future Conference in November 2004 in London.
- de St Exupery, A. (1943) *The Little Prince*.
- Inman, K. (2004) Carers: who cares? http://www.channel4.com/health/microsites/0-9/4health/family/car_carers.html
- Freire, P. (1972) *Pedagogy of the Oppressed*, London: Penguin
- Gadamer, H.G. (1979) *Truth and Method*. London: Sheed and Ward.
- Greenhalgh, T., and Hurwitz, B., (1999) Why study narrative? *BMJ* 318:48-50 (2nd Jan. 1999)
- Jones, M. (2004) *The Awakened Eye: Entering the World With Wonder* www.pianoscapescapes.com (accessed January 2005)
- Page, B. Mori Research Institute Director (2004) 'What they really want' *HSJ* (8th April 2004).
- Princess Royal Trust for Carers (2004) *Primary carers - identifying and providing support to carers in primary care*. London: PRTC
- Routledge, B. (2004) quoted in Davitt, J. 'Used in Class'. *The Guardian* <http://education.guardian.co.uk/elearning/story/0,10577,1233488,00.html>
- Zimmerman, B. (2004) *Wicked Questions: Surfacing differences*. From a talk given at the Clinical Microsystems Conference in October 2004. Also outlined at http://www.plexusinstitute.org/edgeware/archive/think/main_aides5.html (accessed January 2005)