

What do Life Cafes tell us about dying and end of life care

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713. What do 'Life Cafes' tell us about dying and end of life care?

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ABSTRACT *The World Health Organisation (WHO) estimates that the number of deaths worldwide will increase from 56 million to 70 million by 2030. Within the United Kingdom this equates to an increase of 20% over the next five years. Not only will palliative and end of life care services be required to meet the needs of an increasing number of people who are dying but we must also respond to an increasing number of people who are dying from complex, long-term conditions such as cancer and dementia. This paper reports the findings of the first phase of a study undertaken by design researchers at Sheffield Hallam University to inform the development of new and flexible models of care that are responsive to the needs of an ageing population with increasingly complex end of care life needs. Taking the method of 'exhibition in a box', a form of object elicitation developed by Chamberlain and Craig (2013) as the starting point this study curated a series of creative activities, named the 'Life Café' to scaffold thinking and to prompt conversation.*

Keywords: Design, End of Life, Object Elicitation, Method, Conversation, Communication

Introduction

The last two decades have witnessed a demographic change on an unprecedented scale. Medical advances and the treatment of infectious diseases have led to significant increases in life expectancy and the phenomenon of global ageing. However, demographically the world is now at a tipping point and those individuals who have extended their lifespan by 20 and 30 years are now dying. Within the United Kingdom it is estimated that the number of people requiring end of life care services will increase by 20% over the next five years (ONS 2015).

These demographic shifts are placing increasing pressure on existing services, which are already under considerable strain. The fear is that as pressure increases the quality of care people receive may be compromised. These concerns have been fuelled by a number of recent studies. For example, **in one study**, it was found that only 50% of bereaved relatives felt that their loved one had died in their place of choice. In another government commissioned, Review of Choice in End of Life Care (DoH 2015) found that 30% of people who died in hospital received care that was rated by family members as 'poor' or 'fair'. The same review also reported that 40% of those interviewed felt that their family member had not received the dignity or care they deserved.

Research highlights that excellent care is synonymous with a personalized approach where the decisions and personal preferences of the individual are taken into account. However, this is predicated on a system where parity in relation to the quality of care exists across all services. The conclusion of the Ambitions document that *'people want their choices to be real choices based on high quality end of life services being available in all areas and in all settings'* (DoH 2016, 7-8)

In spite of the ambition of government and numerous attempts from health and social care to respond to these challenges, no solution currently exists and a radical rethink is required.

In light of the size and complexity of this challenge, design is well placed to address the issues facing services that address end of life care. Design has always played a significant role within this field but this has tended to focus on environmental design, reflecting a growing body of research that has repeatedly highlighted that the design of the physical environment in hospital and care homes *'can have a direct impact on the experience of care for people at end of life'* (DoH 2008, 17).

This widespread acceptance of the significance of architecture and interior design in relation to physical and psychological wellbeing is perhaps most clearly manifested in the King's Fund *'Environments for Care at End of Life'*. This initiative, funded by the UK Department of Health, was undertaken as part of the broader Enhancing the Healing Environment programme and included over 20 projects focusing on the redesign of specialist and non-specialist hospital and palliative care settings including prisons and mental health units.

However environmental design is just one facet of what design might offer and there is a growing recognition by the broader health community that the potential of design has not yet been realised. Indeed a rapid review of the literature undertaken by Borgstrom and Barclay (2017) highlighted that despite good evidence demonstrating the value of co-design and experience based design methods in capturing patient experience and improving services only 12 papers utilizing these approaches were identified in the context of palliative and end of life care.

About the current research

The study described in this paper is part of a broader enquiry: the Marie Curie Design to Care Programme. The overall aim of the two-year programme is to create the foundations for the future of innovative and tailored palliative and end of life care. A focus of the enquiry is the development of new and flexible models of care that are responsive to the needs of an ageing population with increasingly complex end of life care needs. These models seek to create a system where there is a parity of care across the United Kingdom where different levels of health and social care provision exist.

This paper reports the first phase of the study undertaken by design researchers at Sheffield Hallam University. This research has used design methods to build understanding of the factors community living individuals identify as positive care experiences.

This is very much in accordance with Ambition 6 of the national framework for palliative and end of life care: which places emphasis on community involvement, stating 'each community is prepared to help: people are ready, willing and able to have conversations about living and dying well and to support each other in practical ways' (Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020).

Taking the method of 'exhibition in a box', a form of object elicitation developed by Chamberlain and Craig (2013) as the starting point this study curated a series of creative activities, named the 'Life Café' to scaffold thinking and to prompt conversation.

Whilst traditional qualitative research methods using structured and semi-structured interviews can preference the views of the researcher, who can make assumptions about what the issues are, the creative activities contained in the 'Life Café' can offer individuals the space to reflect, discuss, explore and define the real questions. The activities offer scaffolds for communication because at one and the same time they are both concrete and abstract.

Study Design

Convenience sampling was used and 141 people were recruited for the study from community groups and faith-based organisations including: the Salvation Army, Age UK, Police and Fire Service, local older people's groups and groups from BME communities.

Each session followed an identical structure. After giving written consent, participants were invited to participate in the creative activities that comprised the Life Café. These included interactions with objects / tools to stimulate conversations, word cards, and activities focusing on elements considered important in the context of life and care.

The consent process included permissions to video record/tape the workshop and these recordings were transcribed and analysed using thematic analysis. In order to triangulate the data, the themes were embodied in a series of images and objects that were shared with other groups and stakeholders to check the findings against the views of experts and researchers within palliative care. Where particular objects and images were found to be especially helpful in eliciting conversations these were fed back into the Life Café methodology. As a consequence the Life Café was effectively designed in partnership with participants over the duration of the study.



Figure 1: Life Café set up

Findings

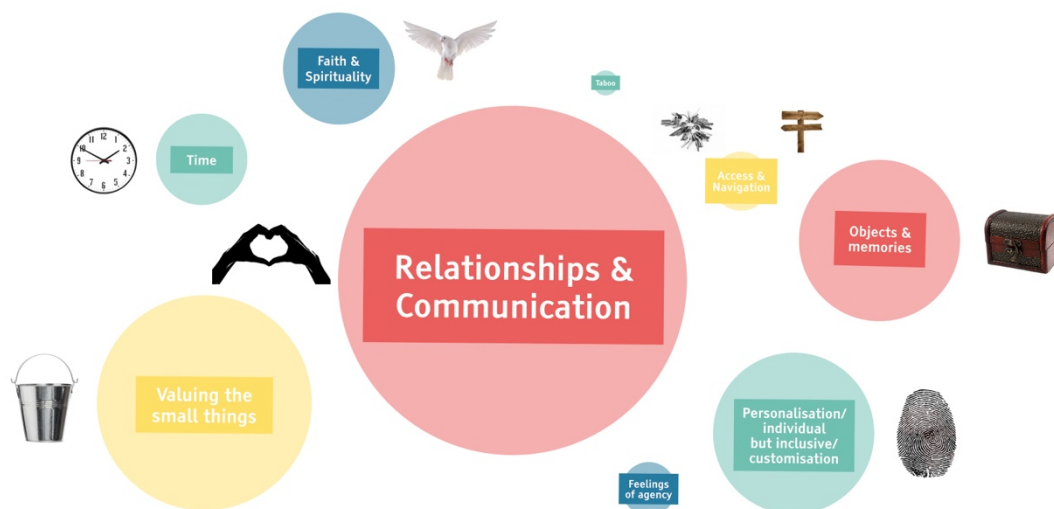


Figure 2: Themes

The strength of the Life Café methodology was that it led to the generation of rich discussion in relation to the importance of meaning and to an articulation of care and the centrality of relationship-centred support. Analysis of the data identified the following themes:

Relationships

Good care was synonymous with relationship-centred care and this emerged as by far the most significant theme within the data. Caring for another person both shaped and was shaped by the relationship. Sometimes this could be positive:

‘It was actually a privilege to care for her [mother]. I learned more about her in those last few days than I had a lifetime before.’

At other times this could be difficult:

‘We were exhausted in the end, emotionally and physically which meant that we said things we didn’t mean and which I really regret now.’

Participants described the impact of wider friendship groups within caring relationships. Two of the most powerful examples of relationship-centred care came from descriptions of community networks. Both related to being cared for in the context of mental health. The first reflected the value attributed to friendships of existing groups individuals were part of; the second described a relationship that was not close and where the person who had taken the role of 'carer' was unaware of the impact they had.

Analysis of the data showed that the broader theme of relationships contained levels of complexity and nuances between notions of care and how these intersected with personal beliefs about value systems and who should offer care:

'There are two types of care; one is looking after your family and children, the other is looking after others that need care.'

The challenge was that care offered through formal health systems could sometimes be regarded as less genuine, and less focused on the person.

Navigation

Navigation and way finding were strong themes that emerged across the research. There were a number of dimensions to this. One the one hand this related to navigation of services and how people found their way through the maze of health care provision to access the care and support that best met individual needs. For example, one individual expressed this in the following way:

'We had been told that my mother had literally days to live. She was very ill by that point but I remember driving from hospital to hospital trying to get a commode to preserve what little dignity she had and all the time feeling that time was running out'

This was linked closely to the importance of understanding where people were within systems and having an overview of what was available at different points in people's journeys through end of life-care services '*knowing what is available when*'.

Within this theme it was not always enough just to know the service but also knowing who to ask, when to ask and how to ask in order to unlock the most appropriate resources.

On the other hand navigation linked to a more existential dimension, less about navigation of services and more about how to navigate the disease in the context of life. One very powerful description was about 'feeling your way' through the experience: navigating the emotional aspects of living with or caring for someone with a life-changing or life-limiting condition, and closely linked to this the more spiritual aspects:

Faith and spirituality

Faith and connection to faith communities was significant for many individuals in our study. Spiritual and religious beliefs shaped individual perspectives of care, particularly end of life care. For some participants these beliefs acted as fundamental motivations for caring for others. For others, faith enabled participants to make sense of events as they unfolded.

Feelings of agency: the ability to adjust and accommodate change

This at times linked to a broader theme around feelings of agency and the ability to exert control over small things even when in the midst of illness. This was not always easy as tensions could arise between letting others in to care whilst still maintaining a sense of agency and maintaining valued roles. Participants regarded seizing opportunities to grow and develop in the face of illness as important. This necessitated making changes to the way particular activities were performed in order to accommodate illness.

The unpredictability of illness and its impact on energy levels, which could vary massively from one day to the next, was seen as having a significant impact on sense of agency. A number of participants spoke then of the value of practical support that came in the form of internet enabled shopping services and telephone banking.

Communication

These emotional and social needs were seen in this study as equal to or even taking precedence over physical needs and a strong theme throughout all the life-cafes was the importance of a holistic approach which recognised and valued the person beyond their illness. Finding a way to hear the voice of the person and the importance of communication was key to this. Indeed, there was a broad consensus across the groups that a key component of good care was communication. The following comment was indicative of many of the broader conversations and responses from participants across the research:

Good care is 'talking, listening, communicating, trusting, consistency, choice and time.'

Personalization /individual but inclusive / customization

Good care was ultimately about listening to and responding to the person's story. Within the Life Cafes participants expressed the notion that it was impossible to describe a set formula for good care as it should be personalised. A metaphor for good care was a chameleon since good care

simply blended into the rest of the person's life and was literally invisible, seamless. Finding ways to elicit this understanding was regarded as being part of the service itself.

Valuing the small things

Inevitably tensions existed in ensuring how to create care services that are responsive to individual needs but have the scope to be applied to a broad population. The study highlighted a number of ways through which care was enacted. Within the workshops individuals described concrete examples of good care; significantly this was not always focussed on major interventions but frequently on detail and small acts of kindness. These aspects did not just relate to care given by family and friends but there were instances where participants who had formerly worked as health professionals who also attached importance to these aspects:

'When I was a nurse I sat with a man that was in the last few hours of his life, there wasn't anything I could do but sit, it was a privilege to be there. This was a huge thing for the family but all I did was sit there and give the time to be there for him.'

Another participant summed up this theme in the following words:

'You don't need huge amounts of electronics, technology or resources, sometimes it's the simple things that make a huge difference.'

Not much about place of care but awareness of value of sensory element

Few conversations during the Life Café workshops related specifically to the site of care although many participants spoke of the value of qualities in the environment that promoted quality of life with particular reference to sensory elements. Individuals spoke of the value they placed on music, on touch and being held.

Discussion

The themes identified in analysis of the data sat well and were congruent with other research in this area. For instance the need for systems to support individuals in navigating services, the importance of seeing the person beyond the label of patient and of the need to find ways to offer individuals facing end of life a sense of agency reflects the broader literature (Kjellgren et al 2015). Relationships within care were seen as central to care and to quality of life.

What was also clear from this phase of the research is that individuals living in communities were a rich source of support and had many resources to offer. Participants attending Life Café workshops not only described the qualities that they valued in the context of care but detailed examples of care they had both given and received. Emotional and practical supports were regarded on an

equal footing to addressing physical needs. This adds further credence to the Government's **Choices document** which recognizes the need to work with and within broader communities to equip individuals and develop their capacity in offering services, 'reaching out beyond the usual networks of organisations and communities to call upon contributions, ideas and actions from a wider spectrum of people' (Choices Document, 4)

Significantly individuals who participated in the Life Cafés identified the value of feeling heard within the research and the method itself offered people the opportunity express this:

'This has made an incredible difference to me today, to be able to share these things and to listen to you all.'

Death is a taboo subject, and attendees at the Life Cafés spoke of the need for more education and awareness. The objects and activities contained within the Life Café had immediate resonances with participants and prompted very personal discussions, unique to the individual. The value of objects and materials in promoting and supporting positive memories was seen as important and this was reinforced in the methodology adopted through the Life Café. Objects spark conversations, stories and hold memories. People talked about things that they had kept, not because of the monetary value, but because they held important memories - often memories of people and relationships.



Figure 3: Objects of importance

Through the iterative cycle, the objects and conversations themselves became part of the methodology and were embodied in the final Life Café Kit which is now being developed so that it can be purchased and independently facilitated in community settings.



Figure 4: Life Café Kit

Conclusion

The Life Café methodology was found to be extremely useful in creating a space where conversations about living and dying well could occur. The enquiry highlighted that care and particularly end of life care is complex and nuanced where great importance should be attached to the details of how care is enacted. Finding ways to build understanding of the experiences and interpretations that individuals have in relation to care is something that practitioners and policy makers need to take into account. The challenge of palliative and end of life care is to find ways of accessing and creating understanding of factors that individuals in receipt of care find important and at the same time creating service models that can accommodate such differences in preferences, values and experiences.

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