

Life Cafe - A co-designed method of engagement

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Life Café - A Co-Designed Method of Engagement

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Abstract: The last decade has witnessed a demographic change on unprecedented scale - people are living longer and with more complex, long term conditions. This paper presents a programme which seeks to rethink how palliative and end of life care can be provided equitably, efficiently and sustainably for future generations. It explores the methodological approach undertaken by university researchers, to engage communities in conversations around a topic often seen as taboo. The community engagement focuses on understanding what is important to individuals in life, care, and end of life. A methodology, named the Life Café, has been developed to gather research in an informal manner within community groups and familiar environments. The Life Café comprises critical artefacts, activities and resources, co-developed with community members developed to answer the research questions. The Life Cafe has become a product that can be used across different services to establish what matters to individuals and enable difficult conversations.

Keywords: Co-design, artefact, end-of-life, conversation, taboo

1. Introduction

Ambition 6 of the national framework for palliative and end of life care states that, '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).

Within the United Kingdom, palliative and end of life care are topics that have risen to the fore in recent years. Fuelled in large part by the dramatic growth in the number of people living with and dying from complex conditions and the prediction of a 20% rise in the death rate within the UK in the next ten years (Choices Document 2015) there is a growing acknowledgement that current models of end of life care need to be re-designed. This paper describes a research project exploring the role of design in the context of end of life care. It focuses particularly on the co-design of an 'artefact led'

method to build understanding of what community living individuals identified as being important in the context of care and particularly end of life care. This approach and associated tools emerging from the research has been named the 'Life Café'.

The World Health Organisation defines palliative care as 'an approach that improves the quality of life of patients and families facing the problem associated with life threatening illness' (World Health Organisation). The definition recognises the importance of providing relief from pain and other distressing symptoms and on the emphasises the importance of acknowledging and integrating psychological and spiritual aspects of care. Of particular significance is that it 'affirms life and regards dying as a normal process' (op.cit).

During the last twenty years, the topic of end of life care has risen to the fore in research and policy. In large part this is as a consequence of the global demographic changes which has seen a dramatic rise in the number of older people aged 65 and over. This trend is not set to change with estimates that by 2036 the number of people aged sixty-five and over is predicted to rise to more than 17.5 million – a 50% increase from the 2016 figure. This is a great achievement, fuelled by advances in medicine and in living standards. Individuals are living longer but at the same time the oldest old are coping with an increased number of long-term conditions and are dying with more complex needs. As a result, existing palliative and end of life care services are struggling to cope. Indeed, a series of studies between 2012-2017 have highlighted significant challenges in the way that care is currently offered.

In the Government funded Review of Choice in End of Life Care (2015) the major finding was that only 50% of bereaved relatives felt that their loved one had died in their place of choice. In another study, it was found that of those interviewed 50% felt that their family member had not received the care they deserved. When placed within the broader context of government funding and predictions that by 2020 there will be short-fall of funding that amounts to 24.3 billion pounds it becomes clear that the way that care is offered and supported requires a significant re-design.

This paper explores the Design to Care Programme, a two-year funded research programme which explores the potential of design in the re-creation of end of life care. 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, radical 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.

A significant element of the programme is its focus on co-design. In the first phase of the work, researchers within Sheffield Hallam University's Lab4Living have focused on building understanding of the experiences of individuals living in the community who have been in receipt of and who have offered care, leading to radical community led ideas for the future of palliative care. This paper explores one of the initial design challenges, which is how to create an innovative approach to elicit these conversations, thoughts and explorations. Methods include the use of critical artefacts and object elicitation – a new approach to addressing the future of palliative care. The results have been the creation of a Life Café kit containing resources and activities to elicit conversations. This paper will present the research process, the risks associated with co-design and the Life Café methodology and how these have been mitigated.

1.1 Questions addressed

Lab4Living, have specialised in co-design and community engagement for over 10 years and so tasked with addressing the following questions within the community setting:

- What does care look like now?
- What are the pressure points?
- What does better care look like?

1.2 Community focus

“The problem with medicine and the institutions it has spawned for the care of the sick and the old is not that they have had an incorrect view of what makes life significant. The problem is that they have had almost no view at all. Medicine’s focus is narrow. Medical professionals concentrate on repair of health, not sustenance of the soul. Yet—and this is the painful paradox—we have decided that they should be the ones who largely define how we live in our waning days.” (Gawande, 2014)

In the book *Being Mortal*, Gawande highlights that modern healthcare has enabled us to live longer lives, yet our societies are not equipped to support the increasing number of frail older adults in our communities. He talks about the power of compassionate institutions in terms of improving quality of life and the need for care to shift to a community focus. There is a shift occurring due to over stretched services and the fact that communities can offer care and compassion needed, if equipped to do so, this isn’t just a medical challenge.

In the UK, the Compassionate Communities movement is gaining traction – “People in a Compassionate Community help care for a dying person through small acts of compassion, supporting the dying person during their end of life, often enabling them to die well and, if possible, at home” (Opac, 2018). Lab4Living researchers have made connections with Palliative Care Consultant and Director Compassionate Communities UK, Dr Julian Abel and will explore how the Life Café fits within this model later in the paper.

“The only way death is not meaningless is to see yourself as part of something greater: a family, a community, a society.” (Atul Gawande, *Being Mortal: Medicine and What Matters in the End*)

A compassionate community not only takes pressure off services, it gives people meaning and connection. This initial research gave the researchers confidence in a community based approach and so next sought to explore what co-design in the field of palliative and end of life care might look like.

2. Co-design

User participation in design began in the 70’s when the term ‘Design Participation’ was introduced in 1971 at the Design Research Society conference. This has since evolved under various titles such as user-centered design, people-centered design, co-design, co-creation and design thinking.

In 2012 Routledge published the *International Handbook of Participatory Design*. It addresses the history of Participatory Design as ‘in the first instance, about designing information technologies that would allow people to change and further develop their work practices to incorporate both the use of computer systems and improved working conditions.’ (Simonsen and Robertson, 2013)

In the 70's user participation was often seen as a box ticking exercise but its' benefits, if facilitated appropriately, have become more and more prevalent in recent years. A designers' role has also shifted in relation to this.

In 2008, Yanki Lee wrote about 'Design participation tactics: the challenges and new roles for designers in the co-design process', and suggested three new roles for designers which "depend more on hands-on experience for Design Participation by putting designers within people's field of everyday life" (Lee, 2008). These roles were:

- **Design Developers** working with design community to transform design processes for participation.
- **Design Facilitators** designing with people to transfer design knowledge to emancipate people to improve their lives.
- **Design Generators** collaborating with professionals to explore design thinking to different implications.

The designers and researchers at Lab4Living operate on all these levels as developers, facilitators and generators and involve stakeholders at every stage of the design process as active members of the team. The more diverse the team, the more inclusive the outcome. Through mapping the diverse stakeholders potentially involved in end of life, expert groups were created and community participant groups identified.

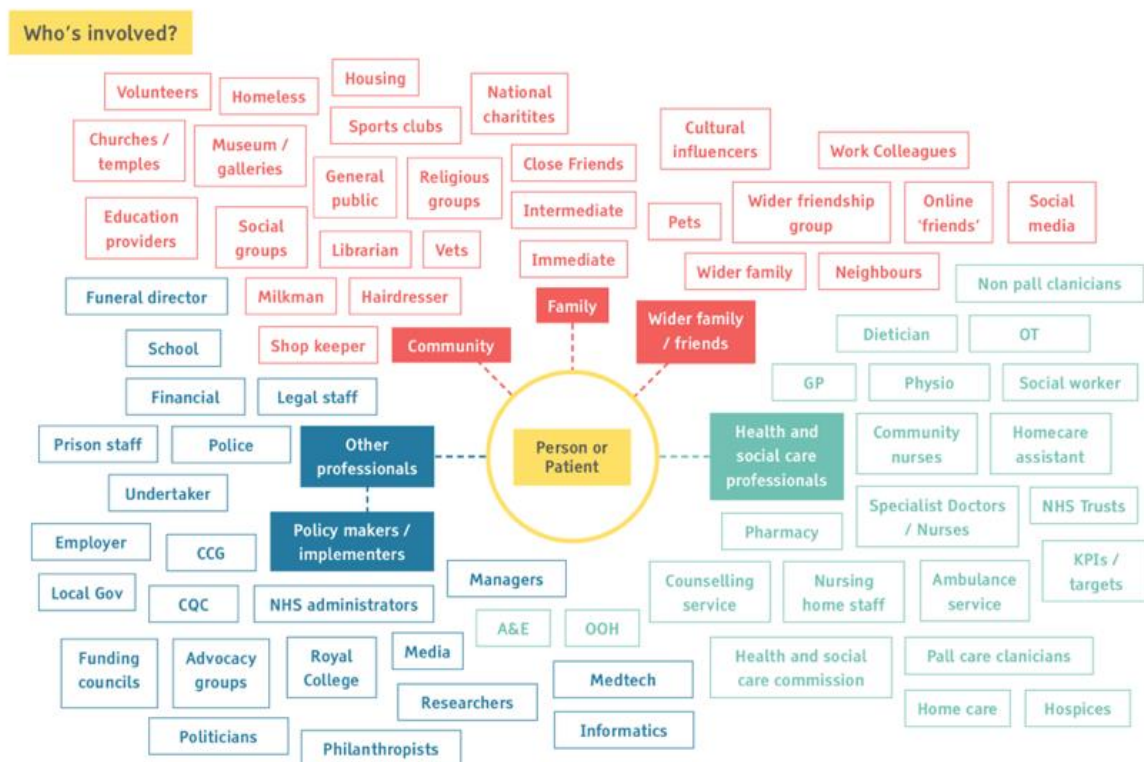


Figure 1. End of life care stakeholder map

3. Design, End of Life and Community

Through the Design to Care Programme the approach was to compliment the great work currently in progress within design. The design world has increasingly seen end of life care as a challenge to tackle; Chief Creative Officer at IDEO, Paul Bennett, told the California Sunday Magazine reporter “I don’t want death to be such a downer,” [...] “It’s just another design challenge” in the interview / article *Death, ReDesigned* (Bennett, 2015). Like Gawande, Bennett talks about seeing the need for change in communities across America;

Now, as many boomers watch their parents die just as Bennett had, accepting the soulless, one-size-fits-all deaths that society deals them, they seem to be rebelling one last time. Everywhere Bennett looked — New York Times opinion pieces and Frontline specials; assisted-suicide laws; the grassroots Death Café movement, where folks get together for tea and cake and talk about their mortality ... he saw his generation striving to make death more palatable, more expressive. (Mooallem, 2018)

In the same article, we hear from BJ Miller, Miller is the executive director of San Francisco’s Zen Hospice Project: “I’d say that humans have thrived by turning every need — every vulnerability — into something in its own right.” Shelter becomes architecture, he noted. Reproduction gets wrapped in romance and love. And “think of all the cultural significance and artistry and labor that goes into [eating].” Miller wanted to bring that same creative power and meaning-making to death, but he had trouble finding a sounding board for those ideas in the medical community. (Mooallem, 2018)

Communities are ready to embrace change, and take risks to establish personal, meaningful end of life – this also cited in Ambition 6 of the national framework for palliative and end of life care, “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*, 2015).

During the Radical change conference: a blueprint for the next 50 years of dying (May 2017), Ivor Williams from the Helix Centre, London, talked about creating a society of carers, “We need to inspire, educate, train and reward future generations to become a society of carers” (Williams, 2017) in order for us to radically rethink the future of end of life care.

Finally, the Innovation Unit are also interested in a ‘community of practice’ and are taking a community based approach to their project, ‘Better Endings’ – “We’re bringing together end of life care experts with excited members of the community to mobilise a new vision of what better endings look like. And, together we are designing solutions that make that vision a reality for people living and dying in Lambeth and Southwark” (Innovation Unit | New solutions for thriving societies, 2018).

All of these examples are pointing to the need for change within the community, and the way to reach effective solutions and change is through community based co-design. Lab4Living have however identified a gap in resources to enable conversations about end of life in the first instance. As with the Design to Care Programme and all of the projects above, difficult conversations around the taboo subject of death need to be facilitated well to ensure true co-design.

Researchers attended a variety of Death Cafés to explore how they enable community conversations and whilst they’re great for breaking the taboo, it was found that they were largely attended by

individuals who weren't afraid to talk about death. A need for a subtler approach was identified, one that explores life and meaning, and so the Life Café began.

The Life Café is an event that one can attend, or held within an existing community group. It is informal and within a safe environment typically with groups that already know each other. The 'Life Café Kit' contains various resources, stimuli and activities to facilitate the event and enable conversations about life, care and end of life care. The kit contains elements which have been categorized as:

- Photos
- Words and emotions
- A-Z (letters and quotes)
- People and relationships
- Sensory objects
- Circles of Support
- Compassionate Communities

This paper will now explore the critical design methodology that resulted in the Life Café Kit.

4. Critical design methodology

4.1. Critical artefacts for expanding imagination

Lab4Living have developed research methods using objects as prompts for conversation for many years. In 2006, the director of Lab4Living published a paper about the 'Designers' Use of the Artefact in Human centred Design' which highlighted "how artefacts can be used as an effective tool to understand users and encourage dialogue" (Chamberlain, 2006).

In this paper Chamberlain highlights that "traditional immersive user research techniques have limitations. It is difficult to understand users' needs and wants in scenarios that are outside their experience. Designers can use artefacts to create new contexts for study – enabling users to explore unfamiliar territory." (Chamberlain, 2006).

This is true for the Design to Care Programme, we can't ask community members to express their needs and wants about their end of life care when they haven't experienced it, therefore artefacts can enable us to stimulate new avenues of thought.

Since the early 2000's, we've seen increasing examples of the use of critical artefacts as research tools – Simon Bowen's thesis 'A Critical Artefact Methodology: Using Provocative Conceptual Designs to Foster Human-centred Innovation' demonstrates the purpose of critical artefacts to "suggest an alternative possibility outside stakeholders' and designer's current understanding. Stakeholders' and designer's engagement with the critical artefact then provokes them to reflect on the limitations of their current understanding that consequently broadens their understanding". (Bowen, 2009) It was felt that this methodology could be used to broaden stakeholder imagination about what is possible in end of life care, but it doesn't directly reflect a person's life, personality and experiences in the way that object elicitation does.

4.2. Object elicitation for insight

Lab4Living often use object elicitation as a method in research because it can give the researcher a rich understanding into a person's life before exploring potential ideas for the future. Other researchers have written about the successful application of this method, for example, a recent paper by Carla Willig, "My Bus Is Here": A Phenomenological Exploration of "Living-With-Dying" demonstrates the use of objects in a research project closely related to Design to Care, where the researcher "generated novel insights into the experience of living with advanced cancer" (Willig, 2015) through using this innovative qualitative method.

Participants were asked to select and bring along to the interview a collection of objects that held special meaning for them during the current phase of their lives... Object elicitation was used to assist data collection in this study because it was felt that by reflecting on their relationship with their chosen objects participants would be able to share more of the quality and texture of their life-world than if they had been asked to talk about their cancer experience in more general and, therefore, more abstract terms. (Willig, 2015)

Objects play a big part in our everyday life, they hold memories, feelings and stories. The researchers wanted to get to know life Café attendees through objects that they described as special to them, and so asked participants to bring in their own objects. These included badges, teddy bears, a mug and even a lock of hair. This was quick way to understand more about the participants and their life, outside of the room, in a rich qualitative way and would be described as object elicitation.

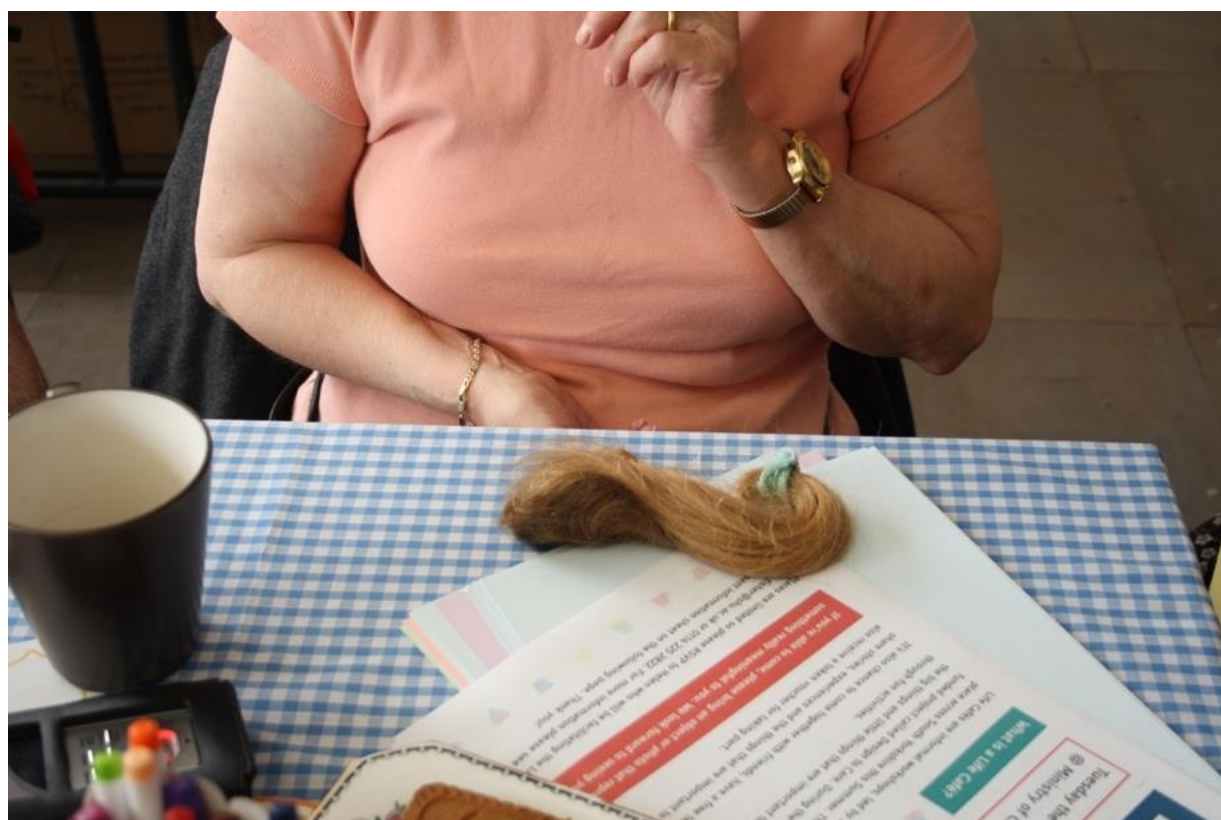


Figure 2: Life Café, Objects of Importance

"Can I show you my grandsons hair? ... He grew it half way down his back ... When he was going to cut it, I said 'I want the hair!'" Do you find that it's the more tactile things that you keep? "Yes!"

This conversation led to others in the group talking about tactile objects that are meaningful to them, that help them feel cared for and safe. The qualities of objects were explored and the difference this has on our experience of care. People shared stories of items they had kept from loved ones that had passed and the meaning behind this.

4.3. Exhibition in a Box

In 2013, Lab4Living developed Exhibition in a Box. 'The principles of the traditional exhibition were distilled into a format that was more flexible, accessible and inclusive. 'Exhibition in a box' (Chamberlain & Craig, 2013) took the essence of the exhibition into a suitcase, à la Duchamp that could be transported to diverse environs including the home. The boxes comprised of everyday objects, photographs and textual material defined through the user-workshops undertaken in conjunction with the earlier large-scale exhibitions in 'engagingaging'. The objects were carefully selected to code, represent and prompt further discussion on themes that had emerged from earlier research.' (Lab4Living.org.uk, n.d.)

In some ways, Exhibition in a Box combines the two methodologies described above. Where object elicitation typically relies on participants having to hand their own meaningful objects, Exhibition in a Box provides everyday objects that we can easily relate to, and express our experiences through. And whilst critical artefacts have typically been designed objects for the research purpose, the objects in the box are more easily recognised as everyday things which we can think critically or metaphorically around expanding our imagination. This slightly more abstract approach is a way for people to be able to talk more freely, using the objects as starters for conversations. It was felt The Design to Care Programme needed a hybrid methodology, like Exhibition in a Box, to engage with community groups in a creative way.



Figure 3: Exhibition in a Box

The use of Exhibition in a Box during other Lab4Living projects such as Engaging and Nestore has proven the efficacy of using objects and the element of surprise to spark conversations about any given topic. It was decided to use the essence of Exhibition in a Box within this research methodology as it successfully offered a scaffolding to talk around enabling more relaxed and open conversations.

From the objects that participants brought to the Life Cafés, and the themes that were emerging during conversations, an Exhibition in a Box was created that was more specific to care and end of life care. The tailored Exhibition in a Box began to evoke even more interesting conversations around faith and spirituality, feelings of agency and valuing the small things in life, for example.

The workshops aimed to establish what good care looks like, tastes like, smells like, feels like and sounds like - to develop a complete sensory understanding of what people understand as good. The objects in this version of Exhibition in a Box therefore have elements of smell, sound, taste, and tactility and are visually stimulating. In the image below, you can see coffee beans, pinecones and a compass. The coffee beans represent sense of smell, daily routine and socializing. The pinecones represent nature, the outdoors and sewing seeds. The compass represents sense of direction, travel and navigation.



Figure 4: Life Café version of Exhibition in a Box

5. Co-designing the Life Café

11 Life Cafés were facilitated with a total of 141 participants using convenience sampling. Recruitment was based on the groups identified during the expert reference meetings as people that may play a part in the future of end of life care services. This ranged from chaplains, faith groups,

coffee morning socials and mixed community groups, all of which included people from diverse backgrounds, demographics and experiences.

The methodology of using objects, analyzing data, generating themes, changing objects has been a form of behind the scenes co-design. Participants have shaped the contents of the box and enabled others to talk about sensitive topics more easily, without really realizing. This iterative co-design process has occurred through every element, activity and resource included in the Life Café Kit, even the graphic design and the packaging design.



Figure 5: Life Café Photographs

The tailored Exhibition in a Box is just one element of the Life Café Kit. The kit contains other activities and resources - the paper will now elaborate on some of these elements.

5.1. Photos

These photographs were selected based on what people told us was important to them, what made them happy, what made them feel safe, cared for and independent. The selections of images grew, developed and has been validated throughout 11 Life Cafés. The photographs have been used in recent Life Cafés and each participant found images they could relate to. Where possible we have used images that have been taken by Life Café participants so that the kit is more real and human rather than the more generic stock images.



Figure 6: Life Café Participant Quotes

5.2. A-Z

It was felt important to include the research participants / community members voice within the kit in various ways, therefore an A-Z of quotes was included. Simply using the quotes enables future users to hear perspectives from others outside of the room and emphasizes that this was co-created with members of the community. Quotes were gathered from participants describing what good care means to them - this resource can be used to understand what people might agree or disagree with, to talk through how others might feel and to consider how people feel who aren't necessarily in the room. There will also be the option for people to continue to add to this in the kit and on the Life Café website/blog (coming soon).

5.3. Activities

The activities have also been co-designed with activity workers in care homes and community members that would be potential Life Café facilitators. On occasions an activity worker was given a box of resources (photographs, objects, words for example) with no instructions but to just have a play and develop their own ways of using them to stimulate conversation about life, care and end of life care. The most successful activities have been included in the manual and descriptions of how to approach these co-written. Here is an example activity from the manual:

If good care was...

Firstly ask the group to share a memory of experiencing, receiving or giving good care. What were the ingredients?

In pairs, using the 'If good care was...' cards, complete the sentences and then report back to the wider group.

Here are a few examples for inspiration:

- If good care was a feeling it would be... warmth, security, a weight lifted, trust, safety, love
- If good care was a texture it would be... soft, warm, all-enveloping, angora, cotton
- If good care was a scent or aroma it would be... warm bread, a light perfume, smell of cleanliness

People can continue to add activity ideas to their Life Café Kit and the website/blog (coming soon).

5.4. Aesthetics and packaging

The design quality of the resources play a part in how they're used, can add value and encourage users to take ownership, feel comfortable and enjoy using them. The kit needed to be accessible and appeal to everyone, no matter what group or demographic. To a certain extent, this meant keeping it visually simple and easy to use, but inspiration was also taken from each workshop group and environment to create something that would fit in naturally in the future, whilst maintaining its own unique identity.

Within the kit there are elements to set the scene. The very first pilot Life Café was facilitated in a Church Coffee Morning group – inspiration was taken from the gingham tablecloths, which felt familiar, friendly and promoted a relaxed Café feel. A gingham tablecloth is enclosed within the Life Café Kit in blue to represent the Marie Curie identity.

During another Life Café with the After 8's women group, it was noted that an element that brought people together, was cake! So, a pop up cake stand was added to the kit. Often within these community settings flowers were used to decorate tables and so a yellow flower and vase was added to the kit to brighten up the table and represent Marie Curie in another subtle way.



Figure 7: Life Café Kit

The Life Café branding incorporates symbols that represent the themes of conversation relationships, love, nature, food and drink. The colour scheme is based on the Marie Curie colours with a complementary pink to represent relationships and love.

The packaging and format of the resources has been shaped by how participants have used previous prototypes and their feedback on usability. Thicker beer mat style photographs have replaced earlier gloss photo-paper versions and the box dimensions adjusted to make carrying easier, for example.

Overall, the designer within this co-design project has been to make the community members ideas possible and able to share with others, in a desirable and sustainable way.

5.5. Iterative Co-design

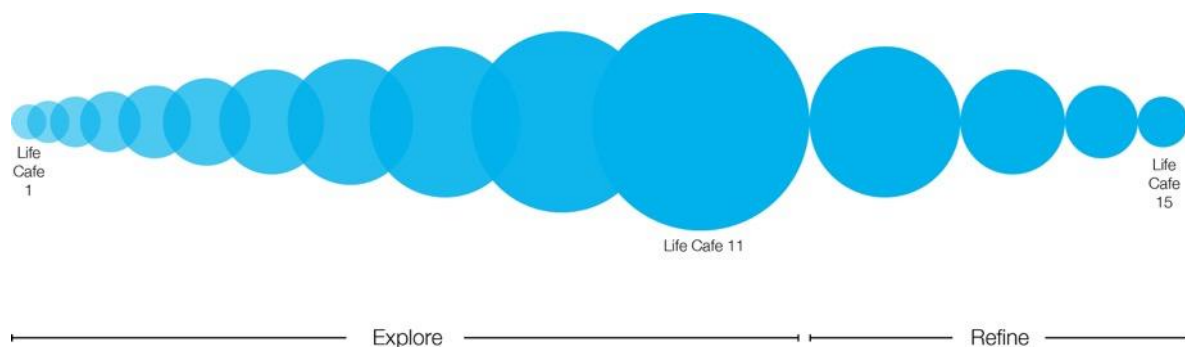


Figure 8: Iterative research and design methodology

The methodology in this paper describes the 11 Life Café's in which we gathered research to address the Design to Care Programme's aims during the 'explore' phase. In figure 8, the depth of research is visualized by the saturation of colour. The size of the circles represents the size of the life café – the amount of resources and activities grew over time, reflecting the feedback from previous life cafes. Once we had reached a point of saturation the 'refine' stage began. Life Café's continued as a way of refining the kit but maintaining the same depth of conversation. Today we have a Life Café kit that can be independently facilitated over a 2-hour period which enables meaningful and rich conversations around life, care and end of life care.

6. Plans for the future

There are currently 4 variations of the Life Café in development:

1. Life Café as a community conversation starter

The Life Café as a community conversation starter is the variation that currently exists and is being trailed within various community groups throughout November and December 2018.

2. Life Café as a research method (Design to Care)

As the Design to Care toolkit requires the Life Café as a research method, a tool to capture conversations will be developed and included in the kit. This will enable healthcare professionals to hear and understand what is required in their locality and what is important to different populations.

3. Life Café as a starting point for Compassionate Communities to grow

A link has been identified between the Life Café and the Compassionate Community model.

A Compassionate Community is a community that provides support to someone who is dying. The community could be family, neighbours, local organisations, a faith group, local businesses or people living in a particular area... People in a Compassionate Community help care for a dying person through small acts of compassion, supporting the dying person during their end of life, often enabling them to die well and, if possible, at home. Palliative care professionals, such as doctors and care workers, are also a vital part of a Compassionate Community. However, to provide the best possible end of life care to someone they need extra support from the patient's community. (Opace, 2018)

The Life Café creatively facilitates the steps before a compassionate community forms, it engages community members and groups and offers a starting point for compassionate communities to grow. The next step is to work with Dr Julian Abel (Director of Compassionate Communities UK) and the community/local organisations/businesses to develop the Life Café to reflect the work and methods used when developing a compassionate community.

4. Life Café for advanced care planning in care homes and hospices

Other avenues have been identified for the Life Café, particularly its use in the Care home and Hospice setting for advanced care planning. This would require a facilitator manual specifically designed for that audience and environment and tools to capture conversations that interface well with current advanced care planning procedures.

7. Risks, insights and conclusions

7.1 Co-design

The unique methodology has enabled the development of something that meets the needs of diverse community groups. Researching and designing with people from different faiths, cultures, and of varying abilities and ages has enabled the creation of activities and resources that can encourage conversations around end of life. The iterative process of co-developing the Life Café gave the product more and more strength after each Life Café. The risk faced was presenting a method that was not complete and still in development – some activities did not work and needed altering following feedback. For example, a Life Café was facilitated with a Somali Women's group who spoke little English, a translator was present but this process seemed to lose the natural flow of conversation. As a result of this, more visual aids such as the emotion cards were added and the written elements minimized.

7.2 Research method

The Life Café was developed primarily as a research method to answer; what does care look like now? What are the pressure points? What does better care look like? This has resulted in an interesting thematic analysis which is influencing the wider Design to Care Programme in the development of other tools to be used within the health and social care system.

There were risks associated with posing these questions within the workshop – it immediately narrows thought and conversation and can be difficult for participants to present ideas and answers without exploring experiences first. The Life Café takes a more organic approach exploring what is meaningful in life and care. Quotes and themes have then been drawn from these conversations and mapped back to the questions but the results are often not specific answers to the questions. Getting the balance of enabling organic conversations yet ensuring research outputs for the wider team was a challenge.

7.3 Engagement method

Once the research outputs had been achieved and a thematic analysis undertaken, the Life Café was developed into a Kit to enable conversation - this was a much simpler process. Feedback was incorporated from participants on usability, which elements were most enjoyable and what worked / did not work, into various iterations of the Life Café Kit. Life Cafés were then facilitated by individuals out of the research group and their insights incorporated into the facilitator manual. It was interesting to provide resources (photos, objects etc.) to facilitators for them to generate their own activities – providing they stimulate conversations about life, care and end of life care. This was a risk in that the resources could have been used inappropriately, but it paid off in widening the potential and adding to the possible uses within the Life Café.

We have seen Ambition 6 in practice – communities are willing and able to have conversations about living and dying, when given the tools to enable this. The subtle approach of the Life Café makes talking about death more palatable as IDEO's Paul Bennett has been striving to achieve. It has also inspired people to think about care in a broader sense and what can be done within the community to care for others, which complements Ivor Williams' statement about creating a society of carers.

“It’s been wonderful to communicate with people on this level, and think about the moments that are not very far for some of us...” (Life Café Participant)

“This has made an incredible difference to me today to share these things and listen to you all” (Life Café Participant)

Other community members could see the potential of Life Cafés for people who are currently experiencing or caring for a person who is at end of life:

“This is the ideal thing for carers ... to learn how to bring them in gently” ... “It should be a mixed group, carers and members of the public” (Life Café Participant)

7.4 To conclude

The Life Cafe as a method of eliciting the experiences of individuals in the context of meaning and care has been very successful. Particularly notable was its ability to enable community groups through this process to identify strength and mobilise knowledge and action. This sits well in the context of building compassionate communities.

The Life Cafe elicited a number of insights of how individuals in the study conceptualise and describe good care, a recognition of the pressure points in relation to delivery. The research has also offered a glimpse of what better care might and could look like in the future. Future research will continue to utilise this method with other groups (health and social care staff, trusts and CCGs, carer groups, community groups etc.) to continue to build understanding in order to inform the redesign of end of life care provision.

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