The subtleties of care: illuminating relational care through design

Greater numbers of people in society need care. However, receiving care disrupts identity, changing the sense of self to being cared 'for' or 'looked after' and can shift the balance where a person may no longer feel independent, but has certain dependencies in their everyday life. These may lead to significant impacts on maintaining day to day life routines and activities. Many of these examples represent transactional care, where a person receives care (in the form of a care package) from another person or service based on their assessed needs, set out in contractual terms in relation to the length and nature of care specified. In research undertaken by Scottish Care, current care models are time-restrictive and mean providing intensive support in the minimum amount of time, leaving little opportunity to provide relational care (Scottish Care, 2017).

Shifting the balance in care

Across the UK, there is a shift in the balance of power and control within health and care systems to support an integrated and person-centred approach that enables people to become active agents in their own care. In Scotland, the vision of the Chief Medical Officer is 'Realistic Medicine' whereby patients become co-managers and are supported to make informed decisions regarding their health and care (CMO, 2015). This vision is reinforced in the new National Health and Social Care standards in Scotland, which states that people receiving care will be involved in all decisions regarding care and support. Underpinned by the principles of dignity and respect, compassion, be included, responsive care, and support and wellbeing, the new standards aim to ensure appropriate care is received and that people have confidence in care providers including workers and organisations (Scottish Government, 2017). Both visions support the need to move from models of transactional care, towards models and systems which support relational, person-centred caring.

In this position paper, we propose that many forms of care can, and should be implicit with greater effort to 'normalise' care by supporting and instilling values of empathy, compassion, and dignity; what we term the 'subtleties of care'. We argue that there is a key role for design in developing asset-based care (Garven et al., 2016) which supports and responds to the aspirations and capabilities of people to enable eudaimonic wellbeing (human flourishing) and prevent the assumption of the 'cared for', dependent role. The creation of asset-based care experiences can also promote a sense of identity that enhances self acceptance, personal growth and control, shifting care from a transactional model of providing and receiving, to a model which values the contribution of the person, self care, wider circles of care (including families and professionals) and the role of the community.

Approaching care from an asset-based perspective involves centring care around the existing capabilities, 'assets' and aspirations of a person. Heavily influenced by the theory of salutogenesis (Antonovsky, 1979), asset-based approaches identify resources which foster health and wellbeing by drawing upon the positive capacities of individuals and communities to protect against negative health outcomes (McLean, 2011). By focusing on the positive capabilities of individuals and communities, health assets have the potential to contribute to quality of life and wellbeing across the lifespan (ibid) and can support individual development in terms of self-esteem, purpose in life, mastery and self actualisation (Rotegard, Moore, Fagermoen and Ruland, 2010). The related concept of eudaimonic wellbeing also asserts a shift in focus from the absence of illness towards the potential and capacity of individuals to achieve and flourish in life. Eudaimonic approaches are considered as being more holistic and have a greater emphasis on meaning in understanding wellbeing (Kashdan, Biswas-Diener, and King, 2008).

Design in care, care in design
The role of design within the context of care, is concerned with systems and technologies, but also with social interactions and experiences, particularly among the 'actors' likely to be involved in organising, providing and receiving care. At a systems level, design involves the development of new services, models, products and technologies that can support care. Design at the interaction and experience level goes beyond the design of an innovative service or technology to consider the impact on the person organising, providing or receiving care in order to support a seamless care experience. At this level, designers are required to develop a 'caring design ethic' based on displaying empathy, sensitivity and a holistic consideration of patients as people, whilst ensuring their repertoire of methods and tools can expand to accommodate this contextual shift (Jones, 2013).

We acknowledge the need to make care explicit at a systems level, rebalancing the workload to foreground care and reduce bureaucratic data collection (Cottam, 2011), often driven by the need to manage risk (Horlick-Jones, 2005). However, at a relational level, between the person and their care giver, this reprioritisation should allow care to be implicit and embedded in all social interactions. Whilst there is a need for designers to span both these domains, we propose that greater emphasis should be placed on understanding where people place value within care interactions and creating the conditions to foreground these moments. Framing the approach around this core objective, designers can ask the right questions and make more pragmatic decisions, and most importantly, appropriate methods to design 'with', rather than 'for' people (French and Teal, 2016).

Illuminating relational care through design
Our work within the Innovation School at The Glasgow School of Art spans formal and informal care in community and acute settings, to design innovative care pathways and services, technology, and systems. We draw from examples of design research in care contexts to reflect on the role of creative, participatory and visual methods, and discuss the relationship between the mindset and skill of the designer in these settings.

In the context of digital health, we employ a participatory design approach to collaboratively design 'preferable' solutions to health and social care challenges. In this context design is not focused on the artefact or end result, but instead is focused on creating an open and participatory process that relies on the direct contextual insight of participants, their creativity and lived experience, and is inclusive of a multiplicity of perspectives (French, Teal, Hepburn and Raman, 2016). Within this collaborative space, problems can be re-framed based on the lived experiences of participants, generating insight based on needs, and raising and answering questions that without the user perspective might previously have been assumed (ibid). Across our work in this context is the overarching aspiration for less obtrusive technology and less 'technology push' to focus on identifying real needs for technology, where technology would be most appropriate within a system or service, and more broadly, the wider impacts in relation to working practices and everyday life. In previous work we have described this as creating a 'community of care' (French, Blom and Raman, 2015) enabled and supported by technology, not as a replacement of existing services and resources, but as a way to facilitate connections and overcome the burden of time consuming tasks that prevent human-based relational care. Across a number of projects, staff providing care have expressed frustration with the time they are required to spend inputting or studying information on screens, reducing eye-contact with the people they are caring for. This theme cuts across a number of different contexts of health and care, including information systems and records, and video conferencing technology to deliver remote care. Just as the technology needs to fade into the background to allow for more natural and relational interactions between the person and their care provider, care needs to be embedded and implicit in conversations centred around the capabilities and aspirations of the person.

In this context, design focuses on supporting the development of technology and systems that redesign care pathways to enable a seamless care experience by exploiting the role of technology more efficiently to create time to care. The evolution of a risk averse culture, in part driven by dysfunctions within the NHS in the late 1990s (Brown and Calnan, 2009) has led to an emphasis on accountability and the creation of audit trails that are time consuming, leaving little time or energy to devote to relational care. The information collected is often seen to be driven by the systemic need to manage contingency, often described by our participants as "ticking boxes" rather than driven by personal care needs. The way in which technology is deployed in the health and care context must ensure that the data collected is meaningful for both the person receiving care and the care provider. As such, the role of the designer shifts from the 'top-down creative' to the 'humble' designer (Slavin, 2016) to engage people as collaborators in the design process and build empathy to translate insights into opportunities that address needs. The designer employs a flexible, adaptive approach to identify the most appropriate method to help people find a way to share their experience, translate, and make this visible and tangible.

In broader wellbeing contexts, our work considers the role of relational care in community contexts. The Curated Care project was undertaken with Highland Hospice in Inverness to explore the role of relational care through volunteering and the impact of this experience on a volunteer's own sense of wellbeing. Through initial meetings with senior clinical and fundraising staff we captured information around the hospice's objectives, infrastructure, and stakeholders into a large asset map (McKnight and Kretzmann, 1997; Foot and Hopkins, 2010) as a means of making available resources visible and tangible. This supported us to consider creative ways to involve members of this 750-strong community in a series of activities to understand their experiences. Following a series of informal introductory meetings, we invited 19 volunteers to take part in a participatory workshop to share their personal motivations, experiences, and aspirations, and collaboratively consider opportunities for enhancing volunteer participation. By drawing out motivations to volunteer – including "keeping busy", "staying involved" in their local communities, and "socialising, whilst helping a good cause" – it became apparent that several volunteers referred to losing friends and family to terminal illnesses and others had experienced health complications themselves and felt "the need to give something back". Appreciation, acknowledgement, and "feeling involved and not anonymous" highlighted the volunteers' senses of achievement and purpose. Interrogating public perceptions, the volunteers noted the need to move away from the old idea of standing outside a shop collecting money towards something more "innovative and compelling" and accentuated "the power of word-of-mouth" as a promotional strategy to extend volunteer participation to a younger demographic. Reflecting on the personal and professional stories that were shared, the volunteers collectively identified an illustrative book as an opportunity to promote Highland Hospices' work across the region; communicate the benefits of volunteering at individual, community, and organisational levels; and the importance of informal care in remote and rural areas. Through a process of consultation, feedback, and iteration, we co-created textual accounts and watercolour illustrations for the book. This centred on a series of Volunteer Portraits, echoing Wright and McCarthy's descriptions of narrative vignettes (2008). As "short pen pictures of people in a setting" employed by researchers to "capture the felt experience of working in a particular place", narrative vignettes offer a glimpse into their "practical, intellectual, and emotional world" and seek to evoke empathic responses from their readers (2008: 642).

Employed by Highland Hospice as a touch-point in their recruitment initiatives, the illustrative book contributes a creative mode of dissemination that has transferable applications in diverse and distinct contexts as part of an asset-based approach. Reflecting on our development of the asset-based approach, we found that its positively-attuned, appreciative ethos allowed us to adapt visual and participatory methods to introduce our work to Highland Hospice, highlight connections between our aims and practices, collaboratively shape appropriate activities, and together embark on a joint process of learning and discovery

(Foot and Hopkins, 2010). As an asset-based approach "does not provide a quick solution to developing community cohesion and resilience, but an alternative mind-set" (Baker, 2014), it is important to emphasise that our objectives in Curated Care were not concerned with co-designing solutions to identified problems, but rather, to better understand volunteers' motivations, experiences, and aspirations and to consider ways to enhance volunteer participation together.

Conclusion

There is a key role for design in addressing the complexities within the care context towards developing future models that support relational care underpinned by core values such as empathy, compassion and dignity. As society continues to be driven by technology and ever-increasing technology consumption, it will become crucial for designers to maintain an ethical approach when considering the role of technology within sensitive contexts such as health and care. Our approach is underpinned by participatory design's democratic values, which view participation as building on primary knowledge, expertise, and tradition to operate as a springboard for envisaging future scenarios (Steen, 2013; Vines et al., 2013). Pursuing our projects with an open mind, and an asset-based approach redirects design's historical tendency to interrogate deficits, problems, and needs, towards being led by the designer's and participants' collective and cumulative knowledge, skills, and aspirations for a flourishing society. Visual and participatory methods can support designers and researchers to identify talents, resources, and capabilities – which may be hidden or ineffable – from within organisations and communities, and to devise creative ways to share and celebrate these strengths towards illuminating relational care.

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