



Care organising technologies and the post-phenomenology of care: An ethnographic case study

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ARTICLE INFO

Keywords:

Care organising technologies
Caring
Postphenomenology
Relationality
Qualitative case study

ABSTRACT

Care organising technologies are software applications that are intended primarily for informal carers, to help organise, document and coordinate caring work. These may be purchased privately or provided as part of state support. Take-up to date remains low. Based on empirical case studies of three such technologies and drawing on post-phenomenology and political science, we examined people's experience of caring when caring technologies find a way into their lives. Our findings show how care organising technologies have evolved in a political context that assumes informal support will supplement and sometimes substitute for state support. Technologies were largely designed to foreground the technical and organisational aspects of care such as planning meals, coordinating medication, and allocating and monitoring tasks among carers. For carers, the result was often a flattening of the landscape of care such that the socio-emotional work of caring was rendered invisible and relations between cared-for and caregiver were configured in narrow transactional terms. For a small number of carers, the focus on tasks was out of tune with their (often emotionally charged) experiences of care and led to active rejection of the technology. However, we also found examples of caregivers and the individuals they cared for using technologies adaptively to facilitate and embed existing care relationships. In these examples, the material/technical, socio-emotional and bodily aspects of caring were interwoven with the situated context of close, unique and evolving relationships. We conclude that the design and development of caring technologies would benefit by being informed by a broader orientation of caring as a relational practice.

1. Introduction

1.1. Background

Care organising technologies are part of a wider ecology of technologies that aim to support different kinds of (often collaborative) work. They are software applications and portals that are generally intended for lay people but are also used by professional carers to organise, document and coordinate the work of caring for someone. Typically, the technology takes the form of an app on a smartphone; several family members install the same app and link it to an index individual. Each carer can enter data and see what data other family members have entered. Different apps offer slightly different functionality but most have domains to visualise (for example) the cared-for individual's medication doses and timings, shopping needs, and a free-text to-do list.

The vast majority of care in the UK is provided by an estimated six

million unpaid informal carers (Office for National Statistics, 2011), many of whom face financial, social and psychological challenges but struggle to get the support from services that they need (Carers UK, 2016; Beesley, 2006; Brimblecombe et al., 2017). This scarcity of formal care resources dominates current discourse and practice, with increasing pressure on families to step in and provide care for relatives where the state does not (Patrie and Kirkup, 2018; Bottery et al., 2018; Department of Health and Social Care, 2018; HM Government, 2008).

In this context, developers, designers, commissioners and users of care organising technologies typically aim to relieve the pressures of caregiving by enabling people to stay at home without continual face-to-face support, provide a means of monitoring care and reassuring carers, give remote access to information (eg, via online training materials); provide social, emotional and peer support (eg, via social networking sites); and provide online tools for coordinating care tasks, respite, and information sharing (Carretero et al., 2015; Yeandle and Fry, 2010).

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<https://doi.org/10.1016/j.socscimed.2020.112984>

Received 26 April 2019; Received in revised form 8 April 2020; Accepted 9 April 2020

Available online 13 April 2020

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Care organising technologies are often purchased privately but in some cases are provided as part of state support. They are part of a wider field of assisted living technologies (eg, pendant alarms) that have evolved to supplement health and social care services (Carretero et al., 2015; Yeandle and Fry, 2010; Lewin et al., 2010). Such technologies have been introduced in health and social care settings in the context of concerns about the costs of long term care, a search for effective and efficient means by which care systems can respond to the needs of ageing populations and a drive for digitalisation. Such programmes are often predicated on a modernist vision, in which technologies seamlessly integrate with health and social care information systems to enable dignified ageing. That vision remains elusive and contested (Greenhalgh et al., 2012). However, the development of care organising technologies seems likely to grow given the push from policymakers, strong interest from commercial providers, demographic changes, shortages of carers and domiciliary staff and financial strains. Despite this push, use of these technologies appears to be low.

Care organising technologies and the ways in which they may (or may not) support carers have received little attention from researchers (Billings et al., 2013). In this paper, we examine the material, socio-emotional and ethical aspects of caring and how technology mediates these (or not). Drawing on an ethnographic case study, we ask: what are peoples' experiences of caring when care organising technologies find a way into their lives? What are the goals and assumptions underlying technologies designed to support caring? And, in what ways do care organising technologies mediate and/or sustain caregiving?

The term 'care' is often used uncritically, referring simply to involvement of family members and friends in providing care to people who need help in their everyday lives due to age, frailty, disability or illness (Barnes, 2012). In reality care involves a number of related tasks and activities (ie, care as 'labour') as well as emotions and relationships (care as 'socio-emotional'), which all contribute in different ways to identifying and meeting a person's needs (Barnes, 2012; Roberts and Mort, 2009; Pols and Moser, 2009), and bring with them both moral and ethical questions about what 'being human' involves (Tronto, 1993). Our task as researchers is to understand these aspects of care and appreciate how they are configured and practiced through technology.

1.2. Research relating to care organising technologies

Recent reviews of Internet interventions aimed at supporting family or informal carers of stroke survivors (Aldehaim et al., 2016), older adults (Bergstrom and Hanson, 2018; Guay et al., 2017; Wasilewski et al., 2017), people with dementia (Boots et al., 2014; Godwin et al., 2013; McKechnie et al., 2014; Waller et al., 2017), people with cancer (Marzorati et al., 2018), and non-specified carers (Carretero et al., 2015; Sin et al., 2018) have failed to find any that support carers to organise care. We found one review of Internet interventions for carers of people with dementia that identified 40 studies describing 31 different Internet interventions (Hopwood et al., 2018), only one of which included a component to help informal carers organise care (*InLife*, a web-based platform intended to enable caregivers of people with dementia to invite family and friends to share care) (Dam et al., 2017).

A systematic review of social support interventions for carers of people with dementia (Dam et al., 2016) identified (Internet and non-Internet delivered) interventions that included "a key component aiming to enhance social support or recruitment of social network members" (p118). None of the 39 papers identified described technology that could be used by carers to extend their circle of care and/or organise care. Similarly, a systematic review of technology used to communicate between patients, family members and healthcare professionals identified 107 studies (Lindberg et al., 2013), which focused on communication between patients and nurses or other healthcare professionals (n = 83), family members and healthcare professionals (n = 14), and healthcare professionals (n = 10). None of the

interventions facilitated communication between carers or supported carers to organise care.

The lack of studies of care organising technologies may reflect a delay between the development of interventions and their evaluation and reporting. A review of Apple and android stores suggests that few care organising technologies are currently available. Grey literature reports suggest that independent organisations are seeking to fill a widening gap in provision as less than 10 per cent of social care is now provided by councils or the NHS (Humphries et al., 2016). Some individuals providing care appear to be actively seeking out alternative means to support caring; and designers and developers are turning their attention to the potential use of technology to support carers. A number of Internet-based interventions are available to address this demand (eg, *Jointly*, *GatherMyCrew* and *Lotsa Helping Hands* - all web-based applications oriented to organising and sustaining care around someone in need), with existing technologies (eg, *WhatsApp*, a web-based text-messaging service) also being repurposed by carers.

To our knowledge, none of these technologies have been evaluated and reported in the academic literature. Those technological interventions that have been reviewed tend to ignore the work of organising, documenting and coordinating caring and focus instead on educational and peer support opportunities provided by technologies, reporting that carers are generally satisfied with the usability and accessibility of the interventions, as well as online support (Wasilewski et al., 2017; Sin et al., 2018). Effectiveness studies of technologies in health-related fields tend to be somewhat deterministic, experimental and quantitative in design, often based on a conceptual parallel with a drug trial in which the technology is assumed to have an isolatable impact on a predefined outcome variable. This sits oddly with an ecological view that care organising technologies are one component of a dynamic system (and therefore do not have a fixed 'effect size'). Recent reviews of technological interventions for caring indicate potential benefits for carers (eg, increase in self-efficacy) (Wasilewski et al., 2017; Sin et al., 2018; Zarit, 2018). However, studies tend to be of poor quality with a lack of statistical power, use of non-standardised measures, inconsistent outcome measures, high attrition rates, sampling bias oriented to white, middle-class participants and a lack of clarity as to whether carers and patients/clients had any say in designating the primary outcome measure (Boots et al., 2014; Godwin et al., 2013; McKechnie et al., 2014; Sin et al., 2018; Zarit, 2018).

In sum, the current literature on care organising technologies is sparse, methodologically limited and naïve to the social complexities and economic realities of care. Much situates technologies as a means of 'relieving the burden' of caring without engaging with the ethical questions about caring or distinguishing between the emotional and practical aspects of identifying and meeting the needs of others. To help redress this balance, and align with the critical socio-material research tradition, we have sought to bring a critical lens to questions about how 'care' is configured (eg, as practical work, or relational practice) by care organising technologies and question what our interactions with care organising technologies do to us as social and emotional beings, and/or how relations between carer and cared-for are ordered through technologies. We also sought to extend our understanding of the human work and social infrastructure needed to enable care technologies to 'work'. This tradition has used qualitative methodologies to examine technologies-in-use and, for instance, the ethical values embedded in care practices (Mort et al., 2015; Vallor, 2011); the ways in which technologies help to shape the positions of caregivers (Pols, 2012); and how they help to reorder what counts as care (Roberts and Mort, 2009; Mort et al., 2009; Oudshoorn, 2010, 2012).

2. Theoretical approach

We build on the critical literature outlined above to focus our study on the social and political dimensions of technologies-in-use (Mort et al., 2009; Roberts et al., 2012; Lupton, 2014). Our interests lie

in understanding technology-mediated care practices from the perspective of the carer. To this end we also draw on research on the social and ethical implications of technologies which acknowledges that, in order to be useful, these technologies must: be nested in networks of accountable human relationships and responsibilities (Mort et al., 2009; Sorell and Draper, 2012); support empathic design and intimate care (Thomas and McDonagh, 2013; Wherton et al., 2015); and account for disruption to the social and moral orders through which care is understood, negotiated, delivered and experienced (Tronto, 1993; Mort et al., 2015; Vallor, 2011). In contrast to much mainstream writing (which tends to situate technologies as ‘care solutions’), we are less concerned with technology and more with the role of care organising technologies as ‘sociocultural products’, ie, the ways in which identities, relationships and social practices are configured and reproduced via such technologies.

Our work is informed by postphenomenology (Ihde, 1990, 1993). Grounded in the phenomenological commitment to understanding human experiences, postphenomenology focuses on the relationships between users and technologies, asking if and how technology shapes our choices, actions and experiences of the world, and drawing attention to the various ways in which technologies mediate relations between human beings and the world (ie, human-technology-world relations) (Rosenberger and Verbeek, 2015). As Don Ihde, founder of postphenomenology, says: ‘When we humans use technologies, both what the technology ‘is’ or may be, and we, as users undergo an embodying process – we invent our technologies, but, in use, they re-invent us as well’ (2007, p. 243).

A postphenomenological lens allows us to make claims about care organising technologies that are situated, grounded in practical problems and empirically oriented. A focus on the micro-level mediating roles that technologies have in human-world relations aligns closely with the aims of our research programme – Studies in Co-creating Assisted Living Solutions (SCALS) – to ‘de-centre’ technology and instead place at the centre of our analysis the person’s lived experience of illness, the social care micro-systems and the wider health and care systems within which that experience is nested (Greenhalgh et al., 2016). Technologies may be a crucial component of that lived experience and those [micro-]systems, but we analyse them as they emerge and are used as part of the system, not as freestanding objects with an ‘impact’ all of their own.

To link this with the organisational context of care and with wider society, we apply Stones’ strong structuration theory (Stones, 2005), which conceptualizes individuals’ *internal structures* (ie, their past experience, knowledge, beliefs, values, perceptions and so on, along with their ongoing, phenomenological experience of illness and ageing) as recursively linked to (ie, both shaping and shaped by) *external structures* of social norms, rules, policies and so on.

Stones’ version of structuration theory retained Giddens’ original focus on the recursive interplay between (social) structure and (human) agency, but presented this structure-agency relationship as playing out in a dynamically evolving networked system in which human actors absorb and interpret the world as they viewed and experienced it (what he called the “strategic terrain”) and use this (often imperfect) knowledge to guide their social action (Stones, 2005). Technologies can be thought of as elements in this network (Greenhalgh and Stones, 2010). Just as social structures – political, cultural or moral – can be internalised by human actors, they can also be inscribed in technologies (eg, as pull-down menus). Whenever human actors use particular technologies (or choose not to), these inscribed social structures are brought into play. Thus, in particular social situations, the availability and material properties of technologies make certain social actions possible and other actions impossible. The consequences of an actor’s decision to use (or not use) a particular technology has both a short-term influence on the immediate social situation and a longer-term influence on wider social structures.

3. Methods

3.1. Sample and setting

A prerequisite of postphenomenology is a focus on case studies of concrete human–technology relations (Rosenberger and Verbeek, 2015). We undertook a collective case study of three care organising technologies, with the aim of taking a close look at the ways in which technology mediates caring. We focused initially on *Sharing Care* (an online tool oriented to enabling people to form a network of friends and family around someone in need and identify and coordinate tasks), which SH had previously been involved in evaluating, before seeking out two further examples: *Together* (an online and mobile app that aims to enable communication and coordination amongst carers) and *TextMe* (a text messaging and Voice Over IP ([VOIP] service). Collectively, these provide three contrasting examples of care organising technologies that developed at different times, involving different actors, for different purposes (Table 1).

3.2. Participants and data sources

We collected data over a 36-month period (2016–2018). Data sources are summarised in Table 2 and described in more detail below.

3.3. Sampling and data collection

To access people’s experience of care organising technologies, along with practical situations of use (Rosenberger and Verbeek, 2015), we invited a maximum variation sample of 27 users. For *Sharing Care*, contact was initially mediated by the developer and local authority in which the technology was being piloted, who identified use for one person, by a couple who we interviewed on six separate occasions. We broadened our search to include 3 people who were using it in other geographical areas and 3 who had shown an interest in using the technology but then actively rejected it. For *Together*, the charity that owned the technology invited 10 users to talk with us. We interviewed all 10, along with one relative. For *TextMe* we interviewed 10 users that were identified on an ad hoc basis via voluntary agencies, and word of mouth (eg, users of other technologies).

We interviewed all 27 users using a narrative approach to explore why they had come to this technology, their use of it (or not), changes over time and their experience of caring. We supplemented this with 35 stakeholder interviews (eg, with developers), 20 observations (eg, local authority planning meetings), and 43 documents (eg, reports of user activity) to understand how technologies had evolved and were (in some cases) commissioned. We fed back emerging findings to staff, investors and developers of *Together* and *Sharing Care*. In the later stages of the project, SH worked with developers at *Sharing Care* to shape the technology in light of user feedback about design and content (eg, the breadth of tasks listed).

3.4. Analysis

We focused initially on *Sharing Care*, highlighting assumptions underpinning the technology about the nature of caring (largely task-oriented, Table 1), availability of social networks (assumed to pre-exist), and lack of concern with human relations (with the world and with technology). As we broadened our analysis to include *Together* and *TextMe* we were struck by the different underpinning assumptions and the ways these appeared to mediate users’ experiences of caring in very different ways. To examine these differences in depth, we applied a postphenomenological framework to specific cases of human-technology relations.

Postphenomenology includes an extensive toolkit of concepts (Ihde, 1990). The notion of multistability refers to the way that any given technology can have multiple uses, meanings and relations with users,

Table 1
Overview of cases.

	Together	Sharing Care	TextMe
History of development	Developed by a carers charity through a co-design process involving potential users, charity, technology developers, and innovation support	Developed by an SME in response to a call to help coordinate care	Originally a simple, free, text and photo-based messaging system, video/VOIP incorporated later.
Vision of developers	To offer flexible, app-based, up-to-date support for carers in their role as carers, and thus supporting cared-for people.	To facilitate better coordination of care, mobilising resources available in caring networks to organise and deliver care.	To enable democratic human relationships and communication by anyone, anywhere (not necessarily carers or cared-for person)
Configuration of carers/cared-for people	Carers as family members, busy providing and sharing informal care with other people, whilst juggling work and other responsibilities. Cared-for people not necessarily 'tech-savvy' enough to use the app, but potentially involved (as desired and with consent).	Carers as social support, needing to mobilise resources to accurately identify, allocate, carry out and monitor tasks needed to support cared-for person (who was generally not expected to be in the network).	Carers/cared-for people not specifically considered; users are people seeking immediate contact with their social networks in convenient forms.
Distribution and cost	Directly marketed to carers as mobile and online app, downloadable via Apple and Google Play Stores for cost of £2.99 per group of carers, or free via weblink from service providers and employers who pay for use. Limited number of users, growing steadily.	Online app, downloaded via developers' website. Paid for by service providers at a cost in the thousands £ to cover a specified locality/group of people. Very limited use, networks often inactive.	Individual user downloads to device (phone, tablet, laptop) via Apple and Google Play free or minimal cost. Extensive global reach.
Functions and architecture	Profile of cared-for person created by primary carer to share with other users. Includes separate sections for tasks, notes, calendar, medications, and messages etc. Ability to assign tasks to others, check off completed tasks. Integrates with some device features (eg, phone camera). 'Help' feature embedded in app.	Web-based interface. Network of carers created who can post, allocate and review tasks needed and make notes.	Group and individual messaging via text, voice call, video calls, images and other media documents, ability to share user location. Integrated into other device features including contacts, camera, location/maps.
Typical use in our cases	Used by carers across multiple devices (phone, desktop pc, tablet), flexibly used as a formal record (eg, of medication), to manage and schedule tasks and for conversational messaging integrated into family communications; with family	Carers networks typically set up without cared for person; used to post jobs that need doing to request help from other carers and family members. Use on desktop pc or laptop.	Frequently used (alongside other apps) for communications generally, with dedicated groups set up to focus on caring for an individual family member (usually not included in the group).

though the range of stabilities (ie, 'variations') will be constrained by the materiality of the technology. Drawing on user vignettes (examining how technology use is shaped by knowledge, beliefs and values), we examined how different technologies support multiple relations honing in on four types of human–technology–world relations: hermeneutic, alterity, background and embodiment (Ihde, 1990). Hermeneutic relations are those in which the person relates to some form of read-out or visualisation produced by the technology (eg, an MRI scan). Alterity relations refers to technologies that mimic person-to-person interaction (eg, speaking GPS devices). Background relations describe the kinds of relations we have with technologies that are in the background of our everyday activities (eg, fridge). Embodiment relations involve the user's experience being reshaped through the device, with the device itself in some ways taken into the user's bodily awareness (eg, glasses). These technologies can be more or less 'transparent', meaning they fade into the background of the user's awareness. We were also interested in non-use of technology and therefore added a fifth type: dissonant relations ie, where the person relates to the technology through their active rejection of it.

We compared and contrasted different people's first hand experiences (Ihde's individual body, or 'Body 1') of care organising technologies across vignettes, paying attention to the ways in which care organising technologies potentially magnify and reduce certain aspects of users' experience (eg, enabling stronger ties amongst family carers whilst minimising monitoring of tasks). This prompted us to seek to understand more about the ways in which technologies are designed and how this potentially shapes human-technology-world relations. We therefore imported 'technology scripts' (Pols and Moser, 2009) as a sensitising concept to explore how roles and relations prescribed in technologies mediate the practice of caring.

Finally, we drew on wider organisational and institutional data to follow the thread from micro-level user experience of technology to understand how external structures (Ihde's social and cultural body, 'Body 2') shape human-technology-world relations, including what

technologies 'do' to caring as human practice (eg, Tronto (1993)) and to us (individually and collectively) as social and emotional beings (eg, Vallor, 2011).

The research received ethical approval from the University of Oxford Research Ethics Committee. The small number of available care organising technologies meant that those involved in developing them might be identifiable. Hence we changed the names of technologies, altered the settings in which they were used, and combined data into composite cases (Toy-Cronin et al., 2018) (ie, with people and settings fictionalised, but details drawn from real cases).

4. Findings

As set out in Table 1, all three technologies were intended to help people connect easily and efficiently with others, based on the use of online and mobile communication. Those designed to help with caring focused on coordination of tasks and people: *Sharing Care* enabled users to create a care network and identify, allocate and monitor tasks required to support the cared-for person; *Together* additionally offered areas to record medication, contact details and post notes and messages. *TextMe* was a generic application that enabled users to create a group and send text, audio and visual (photos and video) messages. Each technology, when in use, was a composite of multiple devices and infrastructures, including (for example) smartphones, computers, tablets, cables and headphones, webpages and apps.

These neutral descriptions provide a sense of what and who care organising technologies might be for. However, they give little sense of the ways in which care organising technologies were understood, used, adapted and/or abandoned (ie, their multistability); or of how they shaped experiences of caring. Our focus on the interactions between people, social worlds and care organising technologies led us to identify three distinct (but not mutually exclusive) ways in which caring, and care organising, was mediated by technology.

Table 2
Overview of data structure and analysis.

Data source	Data collected	First order interpretations	Higher-order interpretations
Organisational case study of the design, development, implementation and use of care organising technologies	<ul style="list-style-type: none"> > Accounts of 35 staff (developers, commissioners, local authority staff, voluntary agency staff) involved in developing and implementing care organising technologies > Approximately 40 h of observation (eg, local authority planning meetings) > 43 documents plus researcher field notes about people and technologies involved in caring and care organising technologies 	<ul style="list-style-type: none"> > Key interactions and interdependencies > Key organisational strategies and how these change over time > Perceptions on the development, design, safety and success of care organising technologies 	<ul style="list-style-type: none"> > 'Scripts' held by organisations/staff about caring and the role of technologies, and how they change over time <p>Assumptions built into the technology about:</p> <ul style="list-style-type: none"> > capability of users/carers > how people interact (inc. with the cared for person) > privacy and consent > caring work and routines > how these all interact
Individual user case studies of care organising technologies	<ul style="list-style-type: none"> > Accounts of 27 users (10 Together, 10 TextMe and 7 Sharing Care) > Descriptive and demographic data of users and those they are caring for > Autoethnographic account (SS) of using Sharing Care and Together, plus screen capture of Together and TextMe interactions 	<ul style="list-style-type: none"> > What is said and done by carers (and cared for person) > Unfolding interaction, strategies for communication and use of technology > How technology shapes and constrains caring > How participants felt 	<ul style="list-style-type: none"> > Internal social structures (what actors 'know' and how they interpret the strategic terrain, including what caring with/without technology means) > Human-technology-world relations (how carers, different technologies and the social world relate) > 'Scripts' held by users about how they should care and how this changes over time

4.1. Situating care organising as a task-oriented process

The dominant use of *Sharing Care* and (to a lesser extent) *Together* was as developers intended ie, to help informal carers to better organise the work of caring (see 'vision', Table 1). For both technologies, this entailed identifying, posting, allocating and monitoring the completion or non-completion of tasks (eg, weekly food shop) amongst a group of carers. Carers accessed technologies via smartphones, tablets and computers (which typically enable embodied human-technology relations (Rosenberger and Verbeek, 2015)), however the predominant human-technology relations mediated by *Sharing Care* in particular was hermeneutic, with most users working with 'task lists' (Table 1, column 3) generated via the technologies (accessible online and/or by text message). This use enabled certain kinds of caring work to become identified, visible and shared.

Sharing Care and *Together* configured caring as 'work to be organised' and prescribed carers as responding willingly to identified needs, responding to tasks that the cared-for person was unable to do, and filling any gaps in public services with unpaid, informal care. Developers, commissioners and staff told us this was as they intended and often talked about supporting those unable to access or pay for services. However, users of the technology tended to be well-educated, professional people with the necessary technical competencies and resources to use the care organising technology and the time, energy and motivation to identify, allocate and complete the tasks. In contrast to many of the people that local authorities were anxious to find support for (often without family or friends to support them), they typically had a support network already in place that was able to help identify and share tasks.

Typical users of *Sharing Care* were Robert and Shirley, both retired in their early 60s, having worked in the civil service all their lives. They are carers for Shirley's Mum, June aged 83, who has Alzheimer's and lives on her own around the corner. They often nip round and check everything is ok in the house, sometimes finding bits of food with a bite taken out because she has forgotten to go back to it. Shirley does all the finances and health appointments. She is the eldest of four siblings, all of whom live close by. They started using *Sharing Care* when it became available through their local authority, using it to identify, share and monitor tasks like 'remind Mum about the cleaner coming' and 'ring Hotpoint about the tumble drier'. At this point their focus was on using technology in a way

that could help them to allocate, share and monitor tasks. Robert and Shirley found it easier to ask (three of the four) siblings using the technology as they could avoid emotionally difficult phone calls and instead focus on the work to be done. They also felt the technology raised the other siblings' awareness about the tasks they did, and they felt less pressured as a result. They created task lists – which turned the focus of the family onto managing the list. The relationship with the technology was predominantly through the read-out: generating, reviewing, monitoring and managing the task list in order to make the tasks of caring apparent and systematically tick them off.

As family relations remained positive and worked well, with increased contributions to and coordination of care, the technology similarly worked well amplifying what was already there. However, as their mother's condition deteriorated, so her care needs changed. Robert and Shirley tried to adapt the technology and use it in different ways, asking the developer for more functions to help co-ordinate different kinds of tasks (eg, a calendar for medications, messaging), but made little headway. Shirley's siblings began to see messages from *Sharing Care* as an intrusion rather than a reminder and stopped responding. As both medical condition and family relations deteriorated so did use of the technology: the family used *Sharing Care* less and less. The *Sharing Care* button on Robert's phone stopped working. He wondered if an app would be easier for everyone and began to search for alternatives. They eventually switched to *TextMe*: they knew how to use it, it was quicker and easier and they could send pictures and communicate in a different way. They now keep track of what needs doing by scrolling back and forth through their online conversation.

Like Robert and Shirley, other users of *Sharing Care* were drawn to the way in which technology might help them to streamline caring. The technology's orientation to tasks drew their attention to monitoring and checking activities allied to caring, and the potential for simplifying care and making it efficient. Carers were situated as active (logging, reviewing and checking tasks) and those receiving care as passive. This emphasis on efficient caring tasks reflected wider discourse (often present in documents and discussions with local authority staff, developers and commissioners) in which the complexity of care work was reduced to purely technical procedures performed by (typically unpaid) carers who are assumed to be available, willing and able to help.

This technological facility to monitor aspects of caring was valued

by a small number of users who liked having an ‘objective’ record of tasks and events. Diane, for example, who worked in a senior corporate role, used *Together* to help her care for her 83 year old mother with multiple interacting medical conditions, whilst also supporting her father, aged 88 and recently diagnosed with dementia. Diane’s parents had moved house to be nearer her and her sister, both of whom used the app to keep track of medical appointments, facilitated by photographing and storing hospital letters to provide what Diane described as “a single source of the truth”. They used information on the app as a ready-to-hand readout of their mother’s interaction with the healthcare system for medical professionals (who often had limited access to the same information). Such uses were common amongst users of *Together*, that (developers told us) was deliberately co-designed to offer flexibility of use (see Table 1), but far less so amongst users of *Sharing Care* (designed by developers with little, if any, input from users) and *TextMe* (designed as a non-care specific technology).

As illustrated by the example of Robert and Shirley’s family, we found that users sometimes struggled to engage with the technology as caring roles and needs changed over time (eg, people dropped out of caring networks, new people came in or those receiving care became more dependent). The focus on a set of tasks, rather than on-going relations, placed limits on the technology and its potential to mediate care. Both technologies offered alternative uses (or *stabilities* (Ihde, 1990)), with users seeking to adapt the technology as their lives and experiences of caring changed. For *Sharing Care*, this was partial: the script underpinning the technology magnified the efficient allocation of tasks and restricted meaningful uptake and use to specific contexts in which practical tasks and efficiency were most relevant. Uptake remained elusive with few changes made to the technology (despite user requests) and *Sharing Care* was frequently abandoned.

4.2. Magnifying the socio-emotional aspects of caring

The amplification of tasks within *Sharing Care* (and the attendant reduction of other potential aspects of caring) typically prescribed a rational response on the part of informal carers to mobilise their own resources and fulfil the tasks allied to caring obligations. Such amplification was not always welcome and rarely (if ever) without effect. For a small number this did not sit well with often highly charged, emotional aspects of caring and led to active rejection of the technology.

Take Corinne, a 50-year old administrator working in the public sector. She was one of four daughters, one of whom had severe learning disabilities and another mental health problems. Her father died several years before and she now cared for her 85-year old mother with dementia who lived locally in warden-assisted accommodation. Corinne came across *Sharing Care* whilst working for the local authority. She choose not to use it, feeling it was set up for “a large Walton family” ie, people who have pre-existing networks of support and positive caring experiences and relationships. Despite this rejection, her limited interaction with the technology had a powerful impact on her, surfacing a complex and difficult family history, and a lack of shared responsibility on the part of her siblings. In theory, she told us “It could be a really good tool”. But, in practice, in her own family she thought “it would just re-open - open up a can of worms”. For Corinne, the idea of introducing technology to help organise care was potentially explosive, configuring relationships and support in positive and continuous terms (and requiring on-going support from siblings), when in reality they were fractious and sporadic. She described being largely on her own in managing her mother’s care, finding it hard to negotiate caring with her siblings (“There’s dirty underwear in the drawers ... I just wonder how dirty and smelly my Mum would have to be. I give her a shower about three times a week. My sister doesn’t”) and managing a heavy emotional burden of caring. Her rejection of the technology had its roots in a difficult family history. What she wanted was not technology but support with negotiating that family history.

For Corinne and other participants in our study, non-use of the

technology was not a neutral choice. Whilst Corinne’s reaction to the technology was, perhaps, extreme; active rejection by other users revealed a specific kind of human-technology relation that we term ‘dissonant relations’, where consideration of the technology magnified the already highly charged emotional experience of caring and led to outright dismissal. Here past experiences contextualised carers’ present experience (what postphenomenologists refer to as ‘sedimentation’), and the technology was perceived as introducing further disruption in an already awkward dynamic. The technology script encouraged users to focus on the efficient allocation of tasks (and who can and should undertake them, Table 1) whilst simultaneously diverting attention from the emotional and relational work needed to support caring. The technology script was thus out of tune with the experience of caring. The result was magnification of emotion (the mere prospect of use being emotionally charged) and rejection of the technology.

4.3. Enabling caring as a relational practice

Together and *TextMe* were designed for different purposes (the former to support informal care activities, the later to enable connection between people generally), with developers centring on the potential of technology to enrich human relations (Table 1). We found that both technologies enabled flexibility in caring roles and practices, and had potential to augment, enhance and even reconfigure experiences of caring. For users (largely middle-aged and well-educated), a key affordance of the apps (used on phones, tablets and computers) was positive reinforcement of the socio-emotional and relational aspects of caring.

As summarised in Table 1, *Together* was developed by a carers’ charity, and co-designed with users in order to identify, evolve and adapt technological solutions to multiple perceived problems of caring, whilst deliberately considering caring in the context of both the family and cared-for person (rather than as tasks delivered by carers, as with *Sharing Care*). What emerged from this co-design process was not only ‘task lists’ (see above), but also much more (eg, calendar, medication record, dynamic messaging) in an attempt to allow different people to engage with the technology (and thereby the experience of care and caring) in a variety of ways. Developers talked about offering multiple interlinked components that could be taken up by different people with different caring responsibilities – and potentially involving the cared-for person - adapted in different ways and combined with other technologies. In postphenomenological terms, the technology was designed to be *multistable* (Rosenberger and Verbeek, 2015). The underlying script centred on the relational aspects of caring, configuring caring as a collective activity (eg, achieved through networks) that is physical, practical and emotional. Developers, commissioners and users talked to us about multiple adaptations and other uses, with paid and unpaid carers variably using the technology (often in combination with other technologies) in ways that enabled them to negotiate – and, crucially, renegotiate – their varied caring roles (eg, coordinating rotas, facilitating handovers, recording adverse events). Underpinning scripts captured practical and emotional aspects of caring and support for both carer and cared-for. For instance, users talked about how the underpinning emphasis on networks of care enabled a shared sense of support, with carers variably telling us how the technology enabled them to organise physical care and additionally “had a way of feeling that you were part of something the app allowed everybody to be looked after but it made [the cared-for person] central ... it was about [them]” (Kate, *Together* user). In sum, the positive socio-emotional aspects of caring could be magnified by these technologies.

Together users were often (but not always) technologically aware and tended to proactively seek out a technology that could support caring. *TextMe* was a generic, free, and widely used text messaging technology that, similar to other non-care specific technologies (eg, mobile phones, pillboxes) had not been designed specifically to support caring. Instead it offered a script about human connections and

relations. We found that users extended prior generic use of the technology to include caring, often in combination with *Together* (and, in one instance, *Sharing Care* – see above). Such combinations made sense: in contrast to *Sharing Care* (largely web-based, and requiring laptop or PC), *Together* and *TextMe* were composites of multiple devices, combining use of the relevant app with (depending on user preferences) smartphones and tablets in ways that offered flexibility (eg, how/where the technology was used), and enabled users to intertwine multiple roles (eg, carer, sister, mother, professional). Rather than simply fade into the background of people's lives, both of these technologies had a role in reshaping experiences of caring and transforming people's capacity to communicate, often over considerable distance.

Margaret, an academic with a nursing background and significant knowledge about health and social care, used *Together* – along with her four siblings – to care for her mother, Beverley, aged 92 and living with Alzheimer's. They had previously used the app when caring for Margaret's father who died of cancer two years earlier. They used *Together* to organise practical tasks for Beverley (eg, around a move to supported housing) and to share information. *Together* was also used in offering and garnering emotional and intellectual support, with use in combination with *TextMe* to facilitate a different kind of communication. The messaging function in particular allowed the family a shared support mechanism and emotional outlet. As Margaret told us, “[After a bad day] I didn't really want to ring anyone and talk to anyone about it ... that would have made it worse. Putting it down on *Together* was a nice way of kind of sharing some of the burden without having to have the conversation.”

Other participants used *TextMe* in similar ways, either alone or in combination with other technologies, enabling them to reorient (and in one case completely rethink) the relationships and communication underpinning care.

This kind of communication amongst families – reliving current and past experiences through the technology, rather than ‘sharing facts’ or coordinating tasks – was possible because of the design of the respective technologies (deliberately intended as relational, and in the case of *Together*, co-designed with carers) and made it easier for them to cope with the on-going pressures of caring. *Together* or *TextMe* became embedded in their daily routines, involving people across locations and reminiscing about family history (eg, memories of places and events). While clearly valuing the record that the technology enabled them to create and maintain (eg, about managing medicines), what came up repeatedly in our data was the value of enduring interaction. As Margaret put it: “*this is about us coping with caring for our elderly parents from a distance ... the family are closer now than they have been in years*”.

Like Margaret, for many of the users in our study these technologies were ‘involving’ and ‘enabling’ (as opposed to ‘alienating’ and ‘constraining’ (Kiran et al., 2015)) in that they enabled an expression of love and care, as well as support for practical tasks (Table 1). Use of the technology meant that a close friend or family member could stay at home and/or stay involved in the lives of those caring for them. In post phenomenological terms, the field of awareness of these carers was significantly reconfigured by technological mediation – their experience of caring was reorganised and enhanced in ways that appeared to enrich their capacity for care. Family and friends found that they had a new way to relate to each other, with multiple forms (eg, text messaging, video, task lists) enabling simultaneous remote communication, connecting people across distance and allowing for new kinds of intimacy and support to be forged.

The ability for multiple people to simultaneously contribute to a conversation, yet each retain control about when and how to respond, was highly valued. People dipped in and out of *Together* and *TextMe*. For many users this offered a new way of ‘being together’ that enabled connection and distance to be simultaneously and positively negotiated. When the technology failed (eg, when connectivity was broken) carers

persisted, using workarounds to continue their conversations and relationships (eg, using another programme to draft messages and later cut and paste them into the app).

Despite positive accounts of these technologies, take-up at the time of writing remained low. Our study involved identifying and speaking with users. Particularly in relation to *Sharing Care*, this proved exceptionally difficult with registered users (ie, family and friends who had registered on the website) being repeatedly re-evaluated as people who had abandoned the technology. Toward the end of our fieldwork period, after over 10 years of trying to garner individual and institutional support, developers abandoned *Sharing Care*. *Together* had around 9500 users in the UK (with an estimated 100–120 users signing up each week), a small proportion of the 7 million estimated carers in the UK.

5. Discussion

This study has revealed how care organising technology holds potential to reshape experiences of caring. The combination of strong structuration theory, postphenomenology and an ethical sensitivity to the ways in which technology mediates the social world has enabled us to do the following. Firstly we have identified the dominant stability of caring, and care organising technologies, as one concerned with the material problems of caring and coordinating (pre-existing) networks of support that willingly find and provide solutions to them. Secondly, we have theorised the relations that carers have with technology and the everyday world around them, challenging the typical view of policy-makers and researchers of hermeneutic technology-world relations (with the user focused on the technology readout, in this case the task-list). Instead we have demonstrated the potential for *multistability* of these technologies (with different users variably taking up, using, adapting and abandoning technology), and for embodied and dissonant relations (with users' experiences either reshaped through their use of the technology or magnified to such a degree that disengagement from the technology is their only perceived option). Thirdly, we have revealed the scripts underpinning technologies and shown how different perceptions of caring (eg, as material problem, or relational process) shape how technologies are taken-up and used (or not), either alone or in combination.

Our focus on care organising technologies, combined with the orientation to postphenomenology and people's everyday experiences of caring and/or technologies, raises wider questions about the nature of care itself. For some involved in developing, commissioning and implementing care organising technologies, the answer to this question appears to relate to the activities, relationships and types of care involved. As with *Sharing Care*, the corresponding enthusiasm for care organising technologies situated them as a solution to problems of an ageing population and reduced social care. Developers (rightly or wrongly) focused on producing technology whose value (coordinating the tasks of caring) was assumed to be self-evident for users, and foregrounded a straightforward and actionable task list. What our findings show is that for a small number of people that very reduced focus (or ‘flattened landscape’ (Roberts and Mort, 2009)) on efficient, task-oriented caring (or ‘care labour’) was exactly what was needed. But for many it was not, as evidenced in the very low uptake and, ultimately, abandonment, of *Sharing Care*.

Most (but not all) of the participants in our study engaged with technology that enabled them to participate in a wider experience of caring beyond *care giving* ie, beyond the direct process of identifying and meeting needs. Rather they sought a broader experience of care, involving not only care giving, but also what Tronto refers to as *caring about* (recognition that action needs to be taken), *taking care of* (recognition that some action is required to respond to the need), and *care receiving* (recognising and understanding the experience of those receiving care and including this in the process of care) (Tronto, 1993). In sum, users actively sought out technology that allowed them to simultaneously and collectively reflect on, acknowledge, actively address

and meet the needs of those they cared for, and adapted their use of technology to facilitate relations. This suggests a deeply ingrained approach to care that involves carer and cared-for in jointly recognising the need for care (attentiveness), accepting that care is needed (responsibility), carefully and ably doing care work (competence), understanding how the cared for person is responding and what it means to them (responsiveness), acting in the best interests of those they care for (trust) and recognising that others are knowledgeable (respect) (Tronto, 1993; Kiran et al., 2015; Sevenhuijsen, 1998; Sevenhuijsen, 2003; Engster, 2007).

We did not set out to explore how such an approach was put into practice in our study. Nor did we include a large sample of users that would enable us to explore variabilities in the extent of caring work, use of technology and the principles underpinning it. Given the sparse and methodologically limited work in this area to-date, we deliberately conducted an ethnographic case study, focused on an opportunistic sample of the small number of current users (largely white and relatively well-educated) who engaged variably with care organising technologies. In one of our themes ('Magnifying the socio-emotional aspects of caring') we report on experiences of only three users. This is undoubtedly a limitation of the study. However, our findings indicate that there is a point to be made: that the practical, social and ethical complexities surrounding the development and coordination of caring need to be taken account of when developing allied technologies. In the case of *Sharing Care*, these complexities were manifest in the magnified emotional reaction to the technology that was designed (at least in part) to treat socio-emotional dimensions of caring as secondary problems that can be tidied up through revisions to the software. Whilst this proved useful for those concerned with physical tasks, the result for some was that the emotional burden of caring was amplified by dissonant relations between the technology and everyday relations of care. In this particular instance it seemed to us that developing care organising technology was, as Pols (2012) puts it, "about clever networking and staying ahead of the competition rather than about collective learning about the best care for whom" (p15).

In practice, managing the complexities of care or putting them to one side was not how most participants in our study approached caring. For many *Together* and *TextMe* users (with some using both technologies), care appeared to be underpinned by many (if not all) of the moral principles outlined above. Technology, and embedded scripts, were adopted or rejected according to the fit with these experiences of care. With the benefit of hindsight, it seems that the enabling potential of *Together* and *TextMe* was informed by use of technology that was anchored in a shared understanding of what mattered to those giving and receiving care, realistic about the principles underpinning everyday caring; human, in that the technology script both recognised and supported interpersonal relationships and social networks (Greenhalgh et al., 2015).

Given the low uptake and adoption of all the technologies in our study and interest from a typically socioeconomically advantaged group with strong social ties, questions remain about the potential for widespread use and the risk of 'intervention generated inequality' (Veinot et al., 2018) (ie, inequality produced by care organising technologies that are more accessible to, heavily used by, adhered to, or effective for those from socioeconomically advantaged groups). If care organising technologies are seen as an important component of the future of care, then developers, commissioners and policy makers need to approach the challenge with a clear understanding of the social relations and interdependencies that underpin caring and a realistic view of what technology can and cannot do. These technologies *cannot* generate effective caring relationships or care networks where these do not exist, nor can they remove the emotional dimension of caring. They *can*, potentially, support and enhance caring relationships and assist with the coordination of care but only if they are inherently flexible (multistable) and incorporate basic concepts – like attentiveness, responsibility, competence, responsiveness, trust and respect – into their

underlying scripts. Such an approach will inevitably be time-consuming, difficult and messy (and perhaps not deliverable at scale), and involve co-design of technologies that acknowledges both carer and cared-for, recognises 'patient work' (Valdez et al., 2014), and includes the practical and socio-emotional aspects of care. If these elements are recognised and embraced then it is possible that care organising technologies can be better designed to support different understandings of care and may provide an important component of long-term care for some individuals and families.

CRediT authorship contribution statement

Sara E. Shaw: Conceptualization, Data curation, Formal analysis, Funding acquisition, Methodology, Supervision, Project administration, Writing - original draft. **Gemma Hughes:** Conceptualization, Investigation, Data curation, Formal analysis, Validation, Writing - review & editing. **Sue Hinder:** Investigation, Data curation, Formal analysis, Validation, Writing - review & editing. **Stephany Carolan:** Investigation, Formal analysis, Writing - review & editing. **Trisha Greenhalgh:** Conceptualization, Funding acquisition, Methodology, Supervision, Writing - review & editing.

Declaration of competing interest

None.

Acknowledgements

Thanks go to all of those who participated in the study, without whom the work would not have been possible. Thanks also go to anonymous reviewers, whose comments helped us to improve the paper.

Funding for the research was provided by a Senior Investigator Award to TG from the Wellcome Trust in its Society and Ethics Programme (WT104830MA) and by the National Institute for Health (BRC-1215-20008).

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