Socio-Technical Resilience for Community Healthcare

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ABSTRACT

Older adults at home frequently rely on '*circles of support*' which range from relatives and neighbours, to the voluntary sector, social workers, paid carers, and medical professionals. Creating, maintaining, and coordinating these circles of support has often been done manually and in an ad hoc manner. We argue that a socio-technical system that assists in creating, maintaining, and coordinating circles of support is a key enabler of community healthcare for older adults.

In this paper we propose a framework called SERVICE (Socio-Technical Resilience for the Vulnerable) to help represent, reason about, and coordinate these circles of support and strengthen their capacity to deal with variations in care needs and environment. The objective is to make these circles resilient to changes in the needs and circumstances of older adults. Early results show that older adults appreciate the ability to represent and reflect on their circle of support.

TAS '23, July 11–12, 2023, Edinburgh, United Kingdom

ACM ISBN 979-8-4007-0734-6/23/07.
https://doi.org/10.1145/3597512.3599720

CCS CONCEPTS

• **Human-centered computing** → *Collaborative and social computing*; *Ubiquitous and mobile computing*; • **Applied computing** → *Health care information systems.*

KEYWORDS

Socio-technical resilience, Community Healthcare, Circle of Support

ACM Reference Format:
Amel Bennaceur, Avelie Stuart, Blaine Price, Arosha Bandara, Mark Levine, Linda Clare, Jessica Cohen, Ciaran Mccormick, Vikram Mehta, Mohamed Bennasar, Daniel Gooch, Carlos Gavidia-Calderon, Anastasia Kordoni, and Bashar Nuseibeh. 2023. Socio-Technical Resilience for Community Healthcare. In *First International Symposium on Trustworthy Autonomous Systems (TAS '23), July 11–12, 2023, Edinburgh, United Kingdom.* ACM, New York, NY, USA, 6 pages. https://doi.org/10.1145/3597512.3599720

1 INTRODUCTION

Older people with complex health needs often rely on a wide network of supporters ranging from healthcare professionals, community members, neighbours, friends, and other types of supporters. This is referred to as their '*circles of support*' [25]. Traditionally, managing these circles of support has been done manually and in an ad hoc manner but software-intensive systems could enhance this in several ways. First, by facilitating *collaboration* between the members of the circle of support. For example, by making sure that observations about the general health of the older person made by

the carers or family members reach the relevant medical staff either in hospital or the local doctor. Second, by the older adults at home to determine if they are improving or deteriorating and offering them *personalised* support. Third, by supporting the *resilience* of the circle of support. Resilience in this context refers to the ability of the circles of support to adapt in the face of change and over time (e.g., change of circumstances of a member of the circle of support) to ensure that the person's support needs are met. Hence, the aim is to integrate people and technology into a single care infrastructure that improves resource utilisation and the quality of care by placing the older adult at the centre (PaC-Person at the Centre) and, when appropriate, giving them control of how their data is used and shared as illustrated in Figure 1.

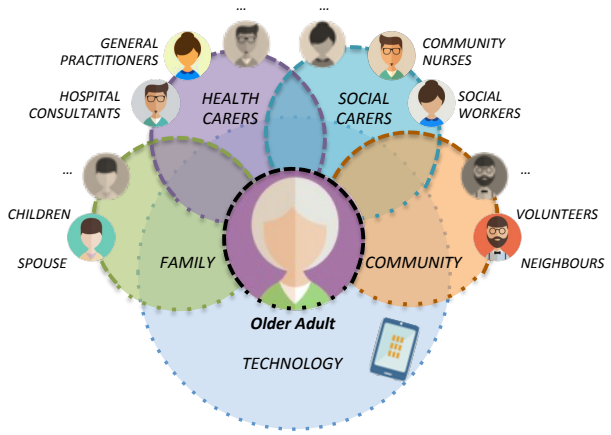

Figure 1: PaC community healthcare

Collecting sensor data to reason about activities has been extensively investigated [4, 35]. Existing approaches to resilient care include automated management of home care solutions [11] that focus on leveraging Internet of Things (IoT) technologies to automate workflows for monitoring and coordinating interactions with home care support teams. However, while IoT aims to provide every person with targeted, optimised, and adaptive support to fulfil their specific needs, this requires software able to capture and accurately represent and reason about people's individual behaviours, moods, and intentions [31]. Adaptive user interfaces [1] aim to engage users by providing them with personalised experiences and new ways to interact with ubiquitous computing technology. Self-quantification provides the means to monitor users' attention [13] and emotions to provide personalised interaction [5]. Existing frameworks for adaptation in socio-technical systems [7] do not support these personalised interactions. Neither do they specifically focus on care requirements and the role of circles of support. Other approaches to connected healthcare [9] focus on individuals or their primary or key supporters. Yet people often have a wide network of supporters ranging from healthcare professionals, community members, neighbours, friends, and other types of supporters.

In this paper, we propose SERVICE (Socio-Technical Resilience for the Vulnerable), a framework that integrates social aspects of targeted, personalised care in the community through circles of support. This socio-technical framework enables representing, reasoning about, and coordinating circles of support, thereby making these circles resilient to changes in context and environment and providing community support to PaC.

While multiple solutions may exist for members of the circle of support to coordinate, the proposed framework seeks to develop a systematic approach for coordinating the circles of support. This systematic support is even more important when those circles are challenged, e.g., with the COVID pandemic. In a recent survey [36], we highlight the role and opportunities that digital interventions provide when co-created with those circles of support. The proposed framework requires novel techniques that are capable of dynamically integrating (technical and social) data and sharing it across the care architecture in order to enhance the PaC's quality of life. To this end, it is crucial to adopt a multi-disciplinary view covering usable and personalised healthcare technologies, software engineering for adaptive systems, machine learning and data analysis, and social psychology. The contributions of this paper are the following:

- Illustrate the role and need of circles of support through a realistic example.
- Present a resilient, re-configurable care architecture that leverages circles of support that deliver care to the PaC.
- Discuss the open challenges of developing and deploying solution for socio-technical resilience.

The rest of this paper is structured as follows. Section 2 illustrates the problem of ensuring socio-technical resilience of circles of support through the example of Betty's case. Section 3 moves into the solution space and presents the multidisciplinary approach needed to address socio-technical resilience. Section 4 describes the SERVICE framework and discusses some of the open challenges. Finally, Section 5 concludes the paper.

2 EXAMPLE: BETTY'S CASE

This section illustrates the notions of circles of support by introducing Betty's case, which builds on several cases provided by Age UK Exeter[1].

Betty is 81 and lives alone in her own home. She has mild dementia and some mobility problems following a stroke several years ago. She has a daughter, *Elaine*, who lives on the other side of the city. Elaine rings every day and sees Betty once or twice a week to do some shopping and her laundry. Betty's son *Derek* lives in another city and is working full time. He rings weekly and comes down to visit his mum every couple of months for a weekend. Derek communicates fairly regularly with Elaine so that he is kept in the picture. Betty goes to Age UK's Park Club on Wednesdays, and is taken there by a volunteer driver. *Diana*, the manager of the Park Club, lets Elaine know if she has any concerns about Betty; but has not had much contact with her as things have been pretty stable over the last year. On the other days, Betty has a half hour visit every lunch time to make sure she has eaten something. This is paid for privately, as the social care assessment did not find eligible needs when it was done two years ago. There is a neighbour *Sally* who occasionally visits Betty, and who has a spare key. On one occasion she alerted Elaine when she noticed Betty's milk still on the doorstep and had gone to check: it turned out Betty had fallen. Betty occasionally, but less and less often now, goes to the local

[1] https://www.ageuk.org.uk/exeter/

supermarket to pick up a bit of shopping; she often sees someone who recognises her from Church or from when she and her late husband used to go to the pub every Friday night. She does not remember names now which she finds embarrassing. Apart from Betty's deteriorating dementia, her physical health has stabilised since the fall, so her GP (General Practitioner) often does not see her for three or four months at a time. Hence, Betty's current circle of support is made up of: (i) her daughter Elaine, (ii) her son Derek at a distance, (iii) the volunteer driver provides an additional pair of eyes once a week and he reports anything of note back to Diana. (iv) Diana at Age UK's Park Club, (v) the care staff who come in at lunchtimes (vi) her neighbour Sally, and (vii) the GP.

While Betty's current circle of support helps her live independently and safely at home, it has several weaknesses as follows.

Lack of collaboration. People in Betty's circle of support do not have a straightforward way of communicating with one another. Elaine is the one most likely to have the clearest view of what is happening, given she has a regular conversation with her mother. However, this view will not be complete or up to date because Elaine does not get daily updates from the care staff. At best she is probably aware that there is not any crisis - as she is more likely to hear from any of these individuals if something goes wrong. Likewise, when the GP sees Betty, she will only know what Betty is able to tell her and how she presents on that day.

Lack of personalisation. Betty's actual needs and preferences are probably not clearly articulated anywhere—although they are hopefully taken into consideration at the day centre and by care workers. Her mood, anxiety level, sense of wellbeing and security are not monitored systematically, and although her food and drink intake is observed, her sleep and the amount she is out of the house or engages with other people when not at the day centre is not.

Lack of resilience. Elaine's husband has been diagnosed with cancer and she has now to care for him as well. There is a need to prevent Elaine from suffering 'carer breakdown' particularly as she becomes a double carer. If she can no longer cope, there are two other people who would need additional system support. However, there is no systematic way for adapting the circle of support to assign Elaine's role and responsibilities to other members.

In this paper we are interested in monitoring, maintaining, and coordinating Betty's circle of support by providing: (i) targeted updates to individuals in the support group, (ii) contingency planning and intervening when things go wrong (e.g., if Elaine is away or unable to visit Betty), and (iii) automation for some of the coordination or tasks achieved by some members of the circle of support (e.g., suggesting delegation of tasks).

Engineering a socio-technical system supporting the above actions requires a multi-disciplinary view covering usable and personalised healthcare technologies, software engineering for adaptive systems, machine learning and data analysis, and social psychology as described in the following section.

3 A MULTIDISCIPLINARY PERSPECTIVE ON SOCIO-TECHNICAL RESILIENCE

The approach for socio-technical resilience we propose in this paper is underpinned by software engineering, machine learning, interaction design, and social psychology. Figure 2 depicts, for each perspective, the specific focus and the main challenge.

Social Psychology provides us with better understanding of social resilience and the mechanisms supporting it so as to define interventions for achieving/enforcing it in practice.

Machine learning provide us with adaptive techniques for analysing data. This would be done by applying adaptive software engineering methods to machine learning.

Software Engineering provides us with methods, processes, and architectures to deal with data-intensive systems to achieve socio-technical resilience. These methods should be generalisable to other domains such as security incidents response.

Interaction Design facilitates user engagement and acceptance of the technology. This might be achieved by developing engaging interfaces that provide users with sufficient information to make informed decisions. It will also be important that these interfaces are inclusive and appropriate for users with limited physical, cognitive, or technical abilities.

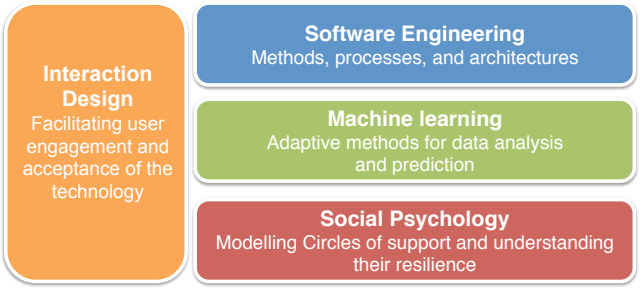

Figure 2: A Multidisciplinary Perspective on Socio-Technical Resilience

Hence, social psychology provides us with the foundation for understanding circles of support and best practices to communicate with their members as well as to sustain those circles. Software engineering helps us define an appropriate architecture for collecting data from the PaC and their circles of support. It also provides methods for reasoning about and coordinating circles of support. It relies on engaging interfaces that facilitate both the communication and the collection of data. Machine learning is used to analyse these data, first for *profiling* (or baselining) to establish norms of behaviours for the PaC and their circle of support (e.g., Betty calls Elaine every morning). Then later, to establish deviations from the 'normal' behaviour (e.g., Betty is calling Elaine sporadically), i.e., *anomaly detection*. As a result, planning is needed to decide on the necessary *intervention* (e.g., nudges for activity). In the following we briefly describe these steps.

4 A FRAMEWORK FOR SOCIO-TECHNICAL RESILIENCE

This section starts by describing the SERVICE framework for socio-technical resilience and illustrates it using Betty's case. It then discusses early results and open challenges.

4.1 The SERVICE Framework

In this section we present the main elements of the SERVICE framework and illustrate their role through Betty's case as depicted in Figure 3:

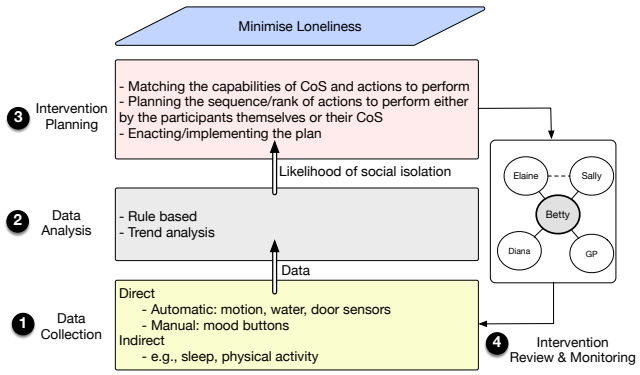

Figure 3: SERVICE framework

❶ *Data Collection.* The aim is to gather data about Betty's well-being and social interactions through deployed sensors or self-reports so as to make informed decisions about her status.
❷ *Data Analysis.* The aim is to examine the data, evaluate the criticality of the situation, and trigger interventions when needed. The intervention can be triggered through specified rules (e.g., Betty specified that she is sad 10 times) or through trend analysis (e.g., Betty interacts less and less with the neighbours). We refer the interested reader to existing work [4] on analysing sensor data in this context.
❸ *Intervention Planning.* The aim is to make decisions on the actions to take that will satisfy the goal, i.e., minimise loneliness, by considering the capabilities of the PaC and their circles of support. Some actions are targeted to the PaC themselves, others need to be carried out by their circles of support. Intervention planning is performed in two steps. First by deciding among all possible intervention actions (specified through a catalogue) which one(s) is (are) the most appropriate in the given context (e.g., get Betty to talk to someone). The second step is about enacting/implementing the chosen actions (e.g., Phone Betty's neighbour Sally to visit her or ask her daughter Elaine to call her). When planning for the intervention one needs to consider the potential effect on the PaC as well as on their circles of support and the ethical choices that are made. For example, nagging Betty's daughter Elaine to visit her because she feels lonely may have a negative effect on Elaine if she is unable to do so due to other commitments.
❹ *Intervention Review and Monitoring.* The aim is to monitor the effect of the deployed interventions, iteratively build knowledge about best measures, and adapt the intervention plans accordingly. With time, we aim to have a better understanding of the mechanisms supporting the resilience of the circles of support.

In order for the SERVICE framework to operate, it relies on several models as depicted in Figure 4:

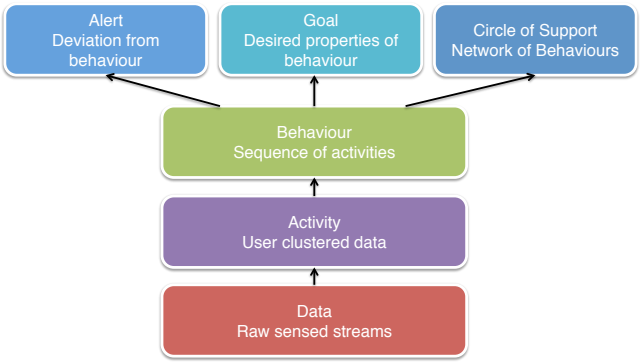

Figure 4: SERVICE model stack

- *Data* to represent raw sensed streams collected directly from different sensors or self-reported by the PaC or members of the circle of support such as number of steps, food intake, or social activities. The challenge is to represent, normalise, and fuse data from heterogeneous sources, especially as new sources of data are added dynamically.
- *Activity* to capture user's clustered data such as sitting, walking, or cooking. The challenge is to to extract activities from incomplete or noisy streams of data.
- *Behaviour* to represent a sequence of activities undertaken by a user. The challenge is to fuse activities in order to learn a user's behaviour and to maintain it up to date as these activities change.
- *Alert* to denote deviation from normal or expected behaviour. The challenge is to identify significant deviations from behaviour and to distinguish them from transient ones so as to trigger suitable interventions.
- *Goal* to represent desired properties of behaviour (e.g., minimise loneliness). The challenge is to capture, represent, and trade off the goals of the different stakeholders (e.g., the PaC, the carer, and the family) and to do so systematically.
- *Circle of Support* to represent a network of inter-connected individuals and groups who serve a role in providing support or befriending to the PaC.

We developed a proof-of-concept app to illustrate the framework and its associated models. The following section discusses the early empirical results using the app.

4.2 Early Empirical Results

In healthcare, it is important to consider ethics and values of all involved in the process [12, 29]. Responsible Research and Innovation (RRI) [26] is an aspiration to conduct research and innovation in an ethically and socially desirable way. By encouraging anticipation of the potential impacts of research on a variety of stakeholders, and responding as necessary to adjust the course of research, we can mitigate potential harms. Our work involved a series of in depth interviews with participants and carers to establish the preferences and values at the heart of the care architecture. This allowed us to explore the limits and the acceptability of information sharing. In addition, we developed several specific case studies where we interviewed members of the wider circle of support–including medical

professionals and care agencies - about what members of a circle of support would like to share (and would be unable to share). The interviews were supplemented by a social group mapping technique [10] and interviews with carers and care staff to produce maps of circles of support.

The prototype was co-developed with those different stakeholders and multiple iterations were used to refine its features. In particular, the prototype allow the PaC to: (i) specify and visualise their circle of support, (ii) report and record their social interactions, (iii) analyse their mood and relate it to social interactions, and (iv) receive recommendation for relevant social activities and interaction. A more detailed description of the prototype and the results of three empirical studies conducted using prototypes of the framework are available at [37]. The key findings are as follows.

- Mapping and visualising the circles of support helps users reflect on their social connections, encourages social insights, and provides reassurance to give and receive social support.
- Interventions that identify opportunities for *in-person* social interactions are valuable to support people help one another.
- Mapping sparse circles of support and the potential lack of responsiveness from others may lead to negative outcomes, e.g., exacerbating the feeling of loneliness. Interventions that recommend groups to join or social activities may increase the resilience of the PaC themselves.
- Reciprocal support is essential to increase PaC's agency. Considering interventions within a network or ensemble of circles of support may yield better care.

4.3 Discussion

While the early results are promising, there are many open challenges that we discuss in the following.

Assurance. To ensure that PaCs and the members of their circles of support have clear care assurances about the satisfaction of care requirements. This requires tools and techniques for analysing the care requirements in the context of the privacy and resource availability constraints. The concept of dependability arguments, originally developed in the context of safety critical systems [21], provides a starting point for investigating the specification and analysis of such care assurances. However, in such complex systems as community healthcare, failure is inevitable [22]. In order to make systems more resilient, it is important to be able to anticipate, inject, and control errors so that side effects that are not necessary foreseen at the design time are better understood when the system is in operation [32].

Managing circles of support. Prior research also underscores the primary importance of user involvement in the design of healthcare systems [19, 23], abiding privacy by design principles [18], not requiring technical expertise (from either PaCs or carers), and allowing people to access information as they choose [2]. We adopt and extend this work to enhance the capacity of circles of support. Immediate caregivers are often overburdened, and need assistance from wider circles of support [28]. It helps to understand gaps in care as resulting from the diffusion of responsibility [8], typically observed when bystanders do not give aid because they do not know if they are the right person to help, or they think other people are already helping. This applies to contexts of healthcare where there are multiple circles of support. For example, one healthcare professional may believe it is another professional's responsibility to do something or one relative may believe another is reminding the PaC about taking medication. We plan to explore alternatives to minimise the effort of self-reporting and diffusion of responsibility as well as to understand implication for privacy better [34].

Identities and social groups. While people often rely on practical assistance from personal relationships, psychologically relevant identities and group membership also play a key role in people's health [20]. Thus we will identify how social groups and interpersonal relationships can be enhanced in a holistic support system—ensuring practical support needs are met alongside psychological needs for belonging, identity, companionship, and sense of purpose or agency. Identities may help guide the planning of Just-In-Time Interventions [24] that require collaboration between (automated) software systems and humans. Existing work on enabling software systems to reason about identities [14] provides a direction for planning identity-aware care interventions.

Values@Runtime. Existing work has promoted the need to consider ethics [30] and values [38] during the development of software systems. Some approaches have been proposed to assess and study values in software engineering [39], to incorporate social values in software design patterns [17], and to measure the impact of values in requirements engineering activities [27]. Values are well studied in human-computer interaction and information systems [6], and especially in healthcare [16]. Existing approaches focus on early stages of the development process [33], with little attention given to the satisfaction of values in deployed software systems. While we used existing participatory techniques during the design and development of the SERVICE framework, we will build on existing work in Values@Runtime [3] to consider values during operation as well as relate them to emotional goals [15].

5 CONCLUSION

This paper proposes the SERVICE framework for supporting collaborative, personalised, and resilient community healthcare. Delivering on the potential of this framework requires future research in several areas, including assurances, identities and intervention planning as well as Values@Runtime.

We believe that socio-technical resilience for community healthcare is a fertile research area, with opportunities for software engineering advances that support wider socio-technical systems development. We have identified a number of challenges and we invite other researchers to collaborate with us in addressing some of these challenges to achieve the full potential of SERVICE.

ACKNOWLEDGMENTS

This work was supported by the Engineering and Physical Sciences Research Council [grant numbers EP/V026747/1, EP/R013144/1, EP/V027263/1]; and Science Foundation Ireland [grant number 13/RC/2094_P2].

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