Towards Care-based Design: Trusted Others in Nurturing Posttraumatic Growth outside of Therapy

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ABSTRACT
Communities and social networks play a significant role in providing care and support for people who have experienced trauma. Increasing use of digital and networked technologies in people’s everyday lives presents opportunities for connecting, communicating, interacting, and caring for one another in new ways, as evidenced in the recent emergence of technologies that are designed to support the post-trauma journey. At the same time, there are distinct shortcomings among the existing technologies in effectively responding to the diverse and changing needs and desires of individuals, including meaningful engagement of trusted others, such as friends and family outside the therapy environment. After examining 83 existing design interventions that provide trauma-related support, this paper identifies six broad themes evident in their approaches: symbolic engagements, creative offerings of comfort and encouragements of self-care, the creative sharing of stories, online communities and agony aunts, the digitisation and re-design of psychology intervention, biometrics and data-driven. It further interrogates related opportunities and challenges to deliberate on how interventions might be designed with and for care at the intersection of communities and technologies, with a focus on engaging trusted others who in various ways and degrees, have a substantial impact on the post-trauma journey beyond therapy.

CCS CONCEPTS
• Human-centered computing → Human computer interaction (HCI)

KEYWORDS
Trauma, Posttraumatic Growth, Trusted Others, Care

1 INTRODUCTION
Trauma is a common experience that can include sudden bereavement, violence and life-threatening situations, such as assault and serious accidents, military-related experiences, or the witnessing of these events [1, 2]. Approximately 50 to 70 per cent of Australians experience a potentially traumatic event in their lifetime [3]; approximately 80 per cent have experienced trauma in the USA [4]. If unaddressed, trauma has the potential to affect families, whole communities, and societies [5]. Identifying ways to address traumatic experiences is difficult, as the impact of trauma is diverse and the journey of those who have experienced trauma is highly individual [6]. Further, throughout the post-trauma journey the care needs of the individual are likely to change overtime, as the individual rebuilds their way of seeing the world and (re-)gains a sense of capability to carry out their everyday activities [6].

While there are traditional and clinical supports such as receiving therapy, those who have experienced trauma can often become overwhelmed with emotions such as anger or despair, or intrusive thoughts and dreams outside of a therapy environment [8, 9]. As such, psychology literature has uncovered many ways to support those who have experienced trauma outside of the therapy environment so that they might effectively cope, or even grow throughout the post-trauma journey [6].

Guided by care theory, which views humans as interrelated and dependent upon one-another [7] and the concept of posttraumatic growth, this paper presents approaches to supporting those who have experienced trauma beyond a therapy environment. In doing so, we seek to outline significant challenges and opportunities for designers of new technologies to consider. Finally, we highlight the need for care theory to be applied to design as a process and outcome for promoting posttraumatic growth, in order to address the complex and long-term needs, wants, and interactions of those who have experienced trauma, and their trusted others.

2 POSTTRAUMATIC GROWTH
Since the formal recognition of post-traumatic stress, the concept of posttraumatic growth (PTG) has gained significant attention within the field of psychology [6]. PTG can present itself as increased self-confidence, enhanced relationships, and a new outlook towards life, often leading those who have
experienced trauma to perceive benefits from overcoming the experience [6]. PTG cannot be created per se, but it can be nurtured in several ways [6]. Upon examining the literature six complementary ways of nurturing PTG have been identified:

1. Strengthening and building of therapeutic relationships, such as those with a therapist, people who have been through a similar trauma, or trusted others such as friends and family [9]
2. Respect for individual perspectives and timings of recovery [6]
3. Allowing for periods of chaos, including psychological and physiological [10]
4. Empathic listening to support narrative development, or the processing of the event into an account [11]
5. Support for meaning-making, which can include a felt sense of value and meaning derived from the experience [12, 6]
6. Reinforcement of the positive aspects identified by the individual [6]
7. Support for appraisal, goal-setting and problem solving [6, 12].

There have been various types of interventions for supporting the post-trauma journey and more broadly, supporting well-being outside of therapy environments. We considered a broad range of interventions produced by individuals and organisations with varying degrees of expertise in PTG, which had a reasonable level of information about their design or social intentions, use contexts, and where available, report on or direct feedback from users. We identified and conducted a thematic review of 83 such interventions. We sourced these interventions from academic research in fields related to Human-Computer Interaction, commercial projects produced by public and private organisations, and existing projects created by individuals and communities that have experienced trauma. More specifically, these interventions were sourced randomly through various means such as the Apple Store, in Spoonful 1 (an Australian arts/health magazine), Australian and international trauma support websites, within design literature, through online articles on emerging technologies and, through online stores such as ETSY2. Only interventions that are made or have related information in English were chosen for review to remain within the scope of this study.

Through the thematic review, six prominent approaches to supporting the post-trauma journey outside of therapy environments have been identified. These approaches of intervention, their opportunities, and limitations are offered as consideration for designers who are seeking to design technologies for supporting post-traumatic growth. These include:

1. Symbolic engagements
2. Creative offerings of comfort and encouragements of self-care
3. The creative sharing of stories
4. Online communities and agony aunts
5. The digitisation and re-design of psychology intervention
6. Biometrics and data-drive

These approaches of intervention are discussed in more details in the following section. Notably, many of the projects reviewed overlap across several of these themes.

After identifying these six prominent approaches, we conducted a systematic review of the 83 projects against the aforementioned seven ways of nurturing PTG. Upon review, we found that rather than allowing for dichotomous grading of successful or unsuccessful in promoting PTG, these approaches entailed a mix of short-comings as well as varying degrees of potential in nurturing PTG. Section 3 presents each of the six approaches in more depth, providing examples of prominent projects that best represent each approach to intervening in the post-trauma journey. It also discusses the complex ways each of these may impact the nurturing of PTG, and key opportunities and challenges for designing new interventions that promote PTG outside of therapy environments.

3 APPROACHES TO SUPPORT OUTSIDE OF THERAPY ENVIRONMENTS

3.1 Symbolic engagements

Symbolic engagements allow for the expression of emotions in response to trauma, such as grief, hope and care. For example, the creative act of folding paper cranes can be found at the Peace Monument Park, Hiroshima, as a symbolic wish for peace after the atomic bomb was dropped by USA in 1945 (Figure 1). Symbolic engagements are often spontaneously and informally developed within the communities, and at times permanently adopted.

Figure 1: Hiroshima’s Paper Cranes at Peace Monument Park, ©Michael Day 3

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1 http://www.artshealthinstitute.org.au/Shop.aspx
2 https://www.etsy.com/
3 http://www.city.hiroshima.lg.jp/shimini/heiva/crane.html
3 By Michael Day (Thousand Paper Cranes) [CC BY 2.0 (http://creativecommons.org/licenses/by/2.0)], via Wikimedia Commons
In Australia, hundreds of individuals placed flowers at Martin Place, as tribute to those who lost their lives in the Lindt Café siege 5. These actions were reminiscent of the Kensington Garden memorial for Princess Diana, where those grieving placed mementos, messages, and floral bouquets (Figure 2). Upon being asked why they laid the flowers, many said they felt they had to take some kind of action, expressing their individual sorrow and their country’s shared grief [13]. Symbolic engagements such as these allow communities to express the depth of grief, their desire to acknowledge a site sacred, and an affirmation of social solidarity [13]. Such approaches demonstrate the importance of individually and communally relevant symbols allowing for the expression of emotion, and playing part in the processing of pain, providing, “…a sense that personal and group trauma must be converted into a community asset, not just a personal asset or catastrophe.” [14]. Through community solidarity, such approaches may contribute to finding meaning in post-trauma journey; a key construct in promoting successful coping and nurturing PTG [6].

Figure 2: Princess Diana’s Kensington Garden Flower Memorial, ©Maxwell Hamilton

Symbolic engagements have been adopted by interaction designers as a way of further engaging communities in the post-trauma journey. However, these projects often augment symbolically relevant symbols, creating new interactions and meanings, resulting in a re-definition of their community or cultural relevance (e.g., [15,16]). It is difficult to determine whether the re-defining of symbolic engagements can contribute to the processing of pain or hope expressed, and the same sense of meaning found when being involved in traditional symbolic engagements, presenting an opportunity for further research.

3.2 Offerings of comfort and encouraging self-care

In recent years, subscription based packages (e.g., Buddy Box) 7 and independently produced zines (e.g.; Heal over Harm) 8 have emerged, offering comfort and encouraging self-care for those who have experienced trauma or other mental health related issues. Many of these zines and subscription based packages are delivered with what could be described as sentimental “treats” such as hand-drawn stickers, temporary tattoos, glitter, decorated envelopes and other self-produced novelties. Piepmeier suggest that zines create a kind of intimacy between the reader and its creator through vulnerability and affection, leading to a kind of surrogate meaningful relationship [17]. Through visual semiotics these zines can also seem like “a gift from a friend” [17]. For example, Heal Over Harm offers stickers decorated with sayings such as “you can do this” and include statements such as “I’m so proud of you” and “hello brave, amazing human”, as a means for offering emotional support. They also offer instrumental supports such as tips and activities which are not necessarily evidence based, rather which are based upon popular pass times or trends, such as “snuggle rat babies”, or “practice your selfie skills”. These approaches may support appraisal, goal-setting and problem solving contributing to the support of PTG, however they do so in limited ways. Encouraging self-management, while being willing to help when tasks are unmanageable is of importance when caring for another throughout the post-trauma journey [6], but these approaches only do the first-mentioned. Furthermore, the “surrogate” relationships between the author and recipient that may be built through these approaches lack the shared-history, and intimacy of relationships that are known to nurture posttraumatic growth [18].

The popularity of zines and self-care packages invite investigation into cultural specific acts of care that may not be evident in psychology literature. Furthermore, designers may consider the potential in engaging the trusted others of those who have experienced trauma in the creation of these approaches, in order to build therapeutic relationships that are known to be fundamental in promoting PTG [9], and offer more relevant and timely encouragements for the individual, rather than that received from a stranger.

3.3 The creative sharing of stories

Creative approaches that support the sharing of stories among those who have experienced trauma are prominent across a range of mediums. Such approaches often involve communicating stories through creative processes, such as the arts, photography and film. This approach can provide the opportunity for skill-building by allowing for the collaboration between those who have experienced trauma with individuals

5 http://www.abc.net.au/news/2014-12-15/sydney-siege-photographs-of-hostage-situation/5969010
6 By Maxwell Hamilton from Greater London, England United Kingdom (Flowers for Princess Diana’s Funeral) [CC BY 2.0 (http://creativecommons.org/licenses/by/2.0)], via Wikimedia Commons
7 https://www.blurtitout.org/buddybox/
8 https://www.etsy.com/au/listing/250154673/heal-over-harm-self-harm-care-pack-self
working in creative fields. By engaging those who have experienced trauma in creative processes, their stories are often communicated in unique and engaging ways, usually with a focus upon celebrating strengths, raising awareness, and skill-building (e.g., HOMEtruths1, and Shero’s Hangout10). The creative process has been found to be beneficial for those who have experienced trauma, as those who have experienced trauma often find it difficult to express their feelings into words [19]. Through these creative approaches to storytelling, these projects may also allow for narrative development, which is a necessary process for the individual to derive meaning from the trauma they have experienced towards PTG [11]. They may also lead to meaning-making, resulting in a felt sense of value through skill-building and the creating of stories valued among their community.

A second approach to storytelling places emphasis on the immersing of others into trauma, and traumatic experiences, in order to build a sense of empathy. For example, That Dragon Cancer11 is a short video game that takes the player through the journey of a family and their three-year old son’s battle with an aggressive form of brain cancer. Similarly, Pry12, an interactive novella presents the “troubled mind” of a veteran after experiencing the Gulf war through a mobile application. While the development of such technologies may benefit the creator in narrative development and meaning making, the benefits and limitations of immersing others in narratives of trauma are difficult to determine without understanding their contexts. If this approach to storytelling does not also present opportunities to take action, the empathic experience may become overwhelming or emotionally painful [20]. Ultimately, when designing for storytelling approaches, consideration is required for those encouraged to engage and experience a sense of empathy with the traumatic experiences, ensuring that they have the resources to cope or take action.

3.4 Online communities, and agony aunts

Other approaches designed to support the post-trauma journey are online communities and agony aunts; being journalists or more recently, artists, who write and publish responses to written expressions of distress. These approaches often foster anonymous and unfamiliar communications between individuals, allowing for the confession of secrets, offerings of advice, or accounts of traumatic experiences (e.g.; Post Secret13, Advice Comics14, Koko15). These approaches could be viewed as a modern alternative to engaging in therapeutic relationships. However, these relationships fostered are with unfamiliar or often anonymous others, taking place online and in writing, rather than through face-to-face contact. The appeal of engaging with such communities may be that they are convenient in regards to cost and location. They may also appeal to those who have experienced interpersonal trauma, which can make it difficult for individuals to trust or be willing to seek help from others [10]. However, without the requirement of response, ongoing emotional involvement, nor an understanding of the complexity of the individual’s circumstance, these online communities could be viewed as “friction-free”, offering “the illusion of companionship without the demands of friendship,” [21].

Studies on similar mental health related communities run through social media networks have found both positive and detrimental interactions, advice, and comments on these sites [22], and at times have been found to reinforce and normalize negative behaviors, [23, 24]. However, these approaches seem to be popular means for receiving kind words of motivation, tips, and advice. It may be that the support presented appeals through their emotional tone, rather than the presentation of dry tips and facts that can be found in online information sources. However, there is room for further exploration into why these online communities are so appealing to many who have experienced trauma.

3.5 The digitization or redesign of psychology interventions

Interaction designers will often collaborate with or draw knowledge from the field of psychology, adapting psychology exercises to suit digital and online formats. These designs often take the form of an online course or app (e.g., MindSpot16, Worry Time17), offering visualized information, storylines with characters that present various experiences of mental health issues, alerts, and reminders to engage in therapeutic activities, competitions, progress tracking, and goals or reward systems. Although often recommended as a compliment to therapy sessions, such approaches can at times fail to recognize the unique interpretations and timing of the individual who has experience trauma, presenting generalized information or sets of activities, that are not necessarily curated to suit the individual.

On the other hand, other digitized or redesigned psychology interventions are aimed at trusted others who might be concerned for an individual who has experienced trauma’s mental wellbeing. For example, Kognito18 and The Check-in App19 provide a platform for trusted others to practice and prepare for conversations around mental health that may take place in real life.

While there are interventions within this approach that seek to engage both those who have experienced trauma and their trusted others, these digitised or re-designed psychology interventions do not usually emphasize collaboration, failing to
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make use of the potential of therapeutic relationships in fostering PTG. This may be due to privacy needs and associated stigma around mental health and therapy engagements. However, there may be opportunity for designers to engage those who have experienced trauma and their trusted others in collaboratively navigating difficult conversations, rather than only in the practicing and preparing for conversations.

3.6 Biometrics and data-driven
Biometrics and data-drive approaches involve technologies that are often used individually (e.g., Spire\(^2\) & Neumitra\(^3\)). These approaches monitor their user’s mental wellbeing, detecting biological indicators of stress, such as erratic breathing. Through doing this they often present amalgamations of gathered data for self-reflection and self-improvement. While wearables for tracking physical health and sleep patterns are well established (e.g., the Fit Bit\(^4\)), human-centered research on how these wearables and mobile applications can support mental health is still in infancy. One study found that these devices can support self-monitoring practices for those with serious mental health difficulties, such as bi-polar disorder and PTSD [25]. These authors suggest that such devices can relax those who are nervous about relapse and need to closely monitor their mental health patterns [25]. Such interventions may also be useful for individuals willing to undertake appraisal, problem-solving actions and goal-setting throughout the post-trauma journey. These interventions often alert users with reminders to care for their wellbeing, or to raise their attention when stress is detected. With little understanding of users’ contexts, such reminders could be disruptive during challenging but potentially beneficial moments, such as when an individual is seeking to process a traumatic event or stressor, which is necessary throughout narrative development [6]. Dow Schüll raises further concerns about the design of health-tracking devices, suggesting that the complexity of data driven technologies is deeply rooted in assumptions made about their consumers and attitudes towards health [26]. She states that, “...once understood as a baseline state temporarily interrupted by anomalous moments of illness, health has been recast as a perpetually insecure state that depends on constant vigilance, assessment and intervention,” [27]. If users are willing, or given the opportunity to reflect upon reasons behind patterns in the data sets and at times challenge the algorithmic logics and values used in the design of these devices, the presentation of personalised data sets may assist users in gaining a more sophisticated understanding of their mental health. However, these approaches tend to position the user in a passive role [26], neglecting individual contexts and timing, and doing little to empower the user in determining their own needs at any given time. Additionally, through alerts and reminders about staying healthy, biometrics and data-drive approaches to the post-Trauma journey may create a sense of disappointment, or add to the potential for chaos already being experienced by an individual throughout the post-trauma journey.

4 THE ROLE OF TRUSTED OTHERS
Through systematic review of the six approaches of intervention for the post-trauma journey, challenges and opportunities have been identified for designers of new technologies to consider when seeking to promote PTG. A common thread across all six approaches is the potential in involving therapeutic relationships in design interventions. Therapeutic relationships beyond therapy sessions, including friends, family, and those who have been through similar traumatic events, are found to be beneficial throughout the post-trauma journey, providing a comforting presence, nurturing and guidance [9, 6]. Trusted others in particular, play a unique role throughout the post-trauma journey, with credibility to promote genuine feelings of love amid chaos [27], and being able to offer care with a foundation of deep connection, intimacy and shared-history [18]. Involvement of trusted others throughout the post-trauma journey has been seen as one of the most powerful tools in reducing the severity of posttraumatic stress disorder; it is crucial for those who have experienced trauma to seek support from trusted others [28]. As previously mentioned, while interpersonal trauma can limit the desire for those who have experienced trauma to seek support from trusted others [10], engaging trusted others, in considered ways, in the post-trauma journey presents significant potential to benefit those who do seek this support. To date, there is little exploration into meaningful engagement of trusted others in designing technologies to support PTG.

Symbolic engagements draw significantly upon relationships within community, while the creative sharing of stories seeks to build therapeutic relationships between those who have experienced trauma and those working in creative fields. There have been limited endeavors to engage trusted others in the creative offering of comforts and encouragements of self-care, in order to underpin these comforts in a shared-history and acceptance. By engaging both those who have experienced trauma and their trusted others in storytelling approaches, rather than just creative experts, there may be opportunity to strengthen existing relationships. Opportunities to collaboratively navigate difficult conversations among those who have experienced trauma and their trusted others were also discussed when examining digitized psychology interventions. Hence, there is significant potential in seeking to involve trusted others in the collaborative use of design interventions that seek to support the post-trauma journey, in order to further nurture PTG.

Figure 3 presents the varying degree to which we found that trusted others are involved throughout the six categories previously examined comparative to one another. We also

\(^2\) https://spire.io/
\(^3\) https://www.neumitra.com/
\(^4\) https://www.fitbit.com/
examined the style of support we observed within each approach across the two-way social support scale [29], which is often used to assess social support experiences. On one end of this scale is emotional support, which includes expressing emotions such as encouragement and praise, reminding the other of their value and worth, and ultimately paying attention to the emotions of another. The other end of this scale is instrumental support, which provide tangible assistance, and information with the aim of solving a problem or accomplishing a task [29]. Examining the approaches through this graph, there is opportunity for more investigations into how trusted others might provide care across the spectrum of support, especially in the instrumental supports offered to those who have experienced trauma. There may be opportunity to take inspiration from popular approaches that involve unfamiliar others, instead engaging trusted others in such approaches in order to create personalized acts of care. This presents opportunity for co-design research, navigating the ways those who have experienced trauma and their trusted others might be engaged in ongoing acts of care throughout post-trauma journey. Through such research, there is opportunity to expand upon the six approaches to supporting the post-trauma journey outside a therapy environment presented in this paper.

### Figure 3: Involvement of trusted others and style of support among identified categories

The role trusted others play throughout the post-trauma journey is complex. While there is strong potential for trusted others to nurture growth in individuals who have experienced trauma, often trusted others find it difficult to understand the best way to offer care [6]. Moreover, trusted others who are concerned for the individual who has experienced trauma often experience decline in mental wellbeing that can present itself as a similar kind of suffering, though with individualized timing and perspectives [30, 31]. Such experiences are inclusive of compassion fatigue, also known as secondary trauma that can lead to feelings of burnout [30]. Therefore, rather than just being a recipients of support, at times the individual who has experienced trauma must offer support to their trusted others, seeking to reduce their trusted others’ feelings of vulnerability and helplessness [32]. Schaefer and Moos describe the impact of trauma as having a “ripple effect” and suggest that not just the individual, but also their trusted others may experience a sense of growth throughout the post-trauma journey [33]. The complex role of trusted others and the potential they have in positively impacting the post-trauma journey presents opportunity for further research and may benefit from design intervention, where supports allow for collaborative and caring acts between those who have experienced trauma and their trusted others.

### 5 Future Directions – Towards Care-Based Design

This paper has identified six categories of approaches to supporting the post-trauma journey outside of therapy environments, examining them and their potential to promote PTG, and presenting several opportunities for designers to further engage trusted others throughout the post-trauma journey. These six approaches presented are not an exhaustive list, inviting further research into the various roles design interventions can play in promoting PTG. Many of the design interventions to date have focused on providing “one-off” or short-term instances of support, which may not effectively serve the complex long-term relationships and interaction within trusted social networks. There is also emphasis placed on building empathy through sharing stories within communities, and at times these interventions present individuals with distressing stories, without presenting possible actions to take in response. New approaches and perspectives are necessary in order to successfully support the diverse scales and types of needs of those who have experienced trauma and their trusted others. One way of achieving this is through understanding care as a concept and practice.

Researchers within design and other related fields have begun to explore care theory in order to deconstruct and come to a richer understanding of care needs and actions within certain communities. For example, influenced by the concept of care, Light & Akama suggest designers guide the creation of opportunities for care to be enabled, where people can reflect, make mistakes, learn and debate [34]. Mol describes good care as requiring an acknowledgment of both the logic of an individual’s circumstance alongside their values, focusing holistically on an individual’s life with careful attentiveness toward their changing experiences [35]. Mol places emphasis on care consisting not of autonomous choices, but of collaborative and continued attempts to refine care actions [35].

Applying care theory to the design of resources for nurturing PTG among those who have experienced trauma and their trusted others allows for the understanding of personalized contexts, needs, and values, with acknowledgement that these will continue to change over time. Furthermore, Koth’s care-in-
action explores how care is interpreted and experienced by those involved in the care acts, understanding that care can easily be misunderstood by those outside of the community or social network [36].

Interrogating care theories and applying them in the process and outcome of designs is not an easy task but a necessary one, especially in order to empower those who have experienced trauma and their trusted others to collaboratively explore appropriate care actions, responding to changing and personalized needs overtime throughout the post-trauma journey. One of the main challenges in achieving this may be to do with understanding that we must design not only for but also with care. This calls for rigorous methodological considerations – for example, how might we explore to further understand the complex, intricate, and individualized care needs and care work that are already taking place? Further, how might we meaningfully engage those who experience trauma and their trusted others to co-create interactions leading to growths and wellness of those directly involved and broader communities? Responding to these and other related questions would require transdisciplinary epistemological approaches and strong ethical research practices. Our study is a small inquiry into the development of such approaches to research and practice.

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