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Original Research Article

Co-Developing Comics to Enhance a Sense of Belonging, Empathy and Agency in the Final Phase of Life

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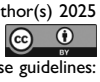
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Amanda Roberts[1]

Abstract

This article explores one way in which the concept of belonging applies to people with a terminal illness. It suggests that retaining some control over life is an important aspect of dying well. It proposes that this control or agency can be developed through social support groups which enable patients to develop a common bond with those in a similar situation. It introduces the PATCHATT community group which co-develops interventions to help patients with a life-limiting illness support one another to make small changes which are important to them (https://www.patchatt.co.uk/). It explores the co-development of a comic strip story, created to exemplify the change-making process, and the learning which arose from this shared endeavour. It uses an analysis of this experience to offer new understandings of the intersection between a discrete identity and social connection in the final phase of life and the distinctive role of bespoke comics in eliciting the empathy which catalyses patient agency.

Keywords

belonging, empathy, agency, comics, palliative care

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Introduction

Dame Cecily Saunders, the founder of the modern hospice movement, rightly asserted the importance of the individual in her well-known statement, 'You matter because you are you, and you matter until the last moment of your life' (https://www.stchristophers.org.uk/about/damecicelysaunders/tributes). This honouring of the unique person remains at the heart of hospice care, with patients being known for who they are, not the illness they've got (Chatland et al., 2021). However, belonging to a wider group is also crucial to a life well lived in its final phases, with friendships between people with a terminal illness being found to significantly improve wellbeing (Bacon, 2019). This is the ontological belonging referred to in this journal's first editorial (Almarode et al., 2024),

[1]Schools of Law and Education, University of Hertfordshire, Herts, UK

Corresponding Author:
Amanda Roberts, Schools of Law and Education, University of Hertfordshire, 3 Fouracres, Letchworth Garden City, Herts, SG6 3UF, UK.
Email: amandajroberts57@gmail.com

where who belongs is shaped by the shared ways of knowing which come with a terminal diagnosis.

I use the word 'belonging' here to mean our desire as social beings to connect with others who value, respect and care for us (Cohen, 2022). Maslow's (1943) hierarchy of needs underlines the fundamental significance of belonging, emphasising its position as an essential building block for the self-fulfilment so prized by human beings. Of course, where we feel we belong can change over time (Girard & Grayson, 2016). Dame Cecily Saunders' statement is grounded in what we might call a person's identity – their particular characteristics and attributes which enable us to distinguish them from someone else (Jenkins, 1996). Although this could suggest identity as fixed, it appears instead to be constantly developing and changing through a life course (Erikson, 1975). A crisis such as a terminal diagnosis can catalyse this shift through a sense of disrupted identity (Exley & Letherby, 2001), as relationships with family and friends and social patterns change.

The Concept of Belonging in Palliative Care

The provision of social support groups within the hospice service is one way of filling the need to belong as we strive to live well in the final stages of life (Allen et al., 2022). In meeting weekly, individuals commit to social practices which mark their affinity with others in a similar position to themselves (Gee, 2001). They become part of an exclusive club, where belonging offers opportunities for reciprocal support and inspiration (Bradley et al., 2023). The quality of empathy, that is, the ability to understand and share the feelings of another, is key here. Much of the literature on empathy in health focuses on the relationship between healthcare professionals and patients - see, for example, Moudatsou et al.'s (2020) literature review. It is the development of empathy between patients which is of interest here, however. A support group for patients with a life-limiting illness is a unique context for bonding. Here, backgrounds, age and interests are irrelevant. Instead, members are bound by their terminal diagnosis, which bridges all other considerations (Putnam, 2000). They become a 'social safety circle' (Slavich, 2020, p. 285), in which they support one another to live well within the constraints of their illness. Living well with a terminal illness naturally involves considerations of how to die well. Whilst the hallmarks of a good death are complex and inevitably vary between individuals (Morgan & Gazarian, 2023), retaining some control over the dying process and preparation for death was frequently mentioned as highly important in Meier et al.'s (2016) comprehensive literature review.

My own understanding of the importance of belonging in palliative care began in 2018. Following a career in education, I began volunteering in the day therapy team of a local hospice. I served refreshments and talked with group members, whilst developing a clear understanding of how day therapy groups might support both physical and social re-habilitation within the boundaries of an individual's illness (Kilonzo et al., 2015; Low et al., 2005). The arrival of the COVID pandemic meant the temporary closure of this day therapy provision, to preserve patient safety. This necessary closure resulted in patient distress, a national phenomenon (Cawley, 2020), with some emotional and physical needs going unmet (Andersson Sviden et al., 2009). Seeking to fill this gap, I set up and facilitated an online weekly meeting for patients previously attending the face-to-face day therapy group.

The group had a loose remit – to support one another to live well. Although not overtly discussed, implicit in this was how to die well. The 2018 Co-op Funeralcare reported only 7% of people to be very comfortable in talking about their own mortality. This reluctance extends to some members of the medical profession, who prefer to focus their conversations

with patients on physical issues (Evans et al., 2014). This is unfortunate, given research suggests patients are keen to have honest, sensitive conversations about end-of-life (Anderson et al., 2013). This was certainly borne out in our support group.

In our group, living well and preparing to die well sometimes meant an individual taking action to change something small in their lives which was nevertheless of great importance to them. The rest of the group provided moral and practical support for this change process. Recognising the power of this peer support, some patients in the group wanted to find ways to help others in their situation to develop their agency, that is, their ability to make a difference to their own and other's lives (Bandura, 1977). These patients joined with clinicians, carers, volunteers and academics to form PATCHATT (Patients Changing Things Together). PATCHATT is a community group which co-develops resources and interventions to help patients with a life-limiting illness support one another to make small changes to their life and care (https://www.patchatt.co.uk/). This article focuses on one of these resources – a comic strip telling the story of a patient called Sylvie.

What We Did

The PATCHATT community group which developed Sylvie's comic consisted of one clinician, two researchers, three members of the public, one carer and two patients. The group was predominantly white and female. We held a series of online meetings to develop our understanding of how to support patients with a terminal diagnosis to lead small-scale change, using the revised MRC/NIHR framework (Skivington et al., 2021) to guide our work. This framework is designed to support the development and evaluation of complex interventions. The framework's authors encourage both pragmatism and creativity in the development and evaluation of new palliative care interventions. Encouraged by this, the PATCHATT community group co-developed a series of comics to support patients to lead a small-scale change which mattered to them. This article explores the co-development of one of these comic strip stories and the learning which arose from this shared endeavour. It offers new understandings of the intersection between a discrete identity and social connection in the final phase of life and the distinctive role of bespoke comics in eliciting the empathy which catalyses patient agency.

Using Comics to Catalyse Belonging, Empathy and Agency

A decreasing belief in their ability to make a difference to their own and the wider world is a distressing outcome of a life-limiting illness for many patients (Exley & Letherby, 2001). Some patient members of the PATCHATT development group wanted to use stories to challenge this idea, to exemplify how people with a life-limiting illness could still bring about small changes which would enhance their well-being. Storytelling has long been associated with both belonging and agency in palliative care. Stories are often central to social support groups, with patients telling each other about their week, their illness, their life. This shores up a sense of belonging, with teller and listener co-operating to understand what is being learned from their own story and those of others (Josephsson et al., 2022). In telling their story, patients re-explore their values, reflecting on what is important to them now and developing the agency to change things (Olsen et al., 2020). Storytelling is also of great value in moving towards more equal partnerships between clinicians and patients. Challenges to individual or societal ways of seeing posed by counter stories (Bietti et al., 2019; Essebo, 2022; Mourik et al., 2021) support this equalisation of power.

Members of the PATCHATT development group asked me to draft appropriate stories to challenge the perceived lack of agency of those with a terminal illness. The stories needed to be

a structured account of events and experiences, created to share this particular message (Anglin et al., 2023). My first attempt at developing a story was a 250-word written piece about a character called Sylvie who was in the final phase of her life. Sylvie is a fictional character. Her story is an amalgam of the experiences of a range of patients with a life-limiting illness known to PATCHATT development group members, personally or professionally. The first story I wrote about Sylvie was unanimously declared 'boring', 'too long' and 'difficult to relate to' by patients in the PATCHATT group. In this they echoed Frosh's (2002, cited in Leitch, 2006) view of the deficiencies of written text in conveying complex beliefs and emotions. In rejecting this first version of Sylvie's story, group members reflected the *Dying Matters* campaign view of the difficulties in finding words to discuss the complex beliefs and emotions related to dying, death and grief and the importance of creating an open culture where this is encouraged (https://www.hospiceuk.org/our-campaigns/dying-matters).

In discussing how to move forward, group members talked of the wide accessibility of visual stories (Woods, 2011). Some members believed stories' power to support feelings of belonging to a community of changemakers (Champion-Smith et al., 2011) meant that a visual version of Sylvie's story would be more likely to encourage people to tell their own story and to make changes to it where possible. The first draft of Sylvie's visual story is shown in Figure 1 below.

This first visual draft again met with strong reactions. Whilst initially enthusiastic about its superiority to the written version, patients struggled to associate themselves with the comic characters as they were portrayed. They thought the 'blobs' looked childlike and felt no connection with them. This was not caused by the common issue in belonging that some felt a sense of connection whilst others felt excluded (Hall, 1996). Instead, no one felt they belonged with Sylvie. McCloud's (2000) argument that the shift from realistic to symbolic drawing enables a wide range of people to connect more readily with comics was problematised here. Clearly, there is a point past which the reader's ability to connect with the presented characters is inadequate to bring about the desired sense of belonging and empathy. The use of the third person in the accompanying text exacerbated this issue. Group members worried that the story did not seem to be owned by Sylvie, reducing any likeliness of reader affinity and therefore any inspirational value. To respond to this, I produced draft 2, shown in Figure 2 below.

This version of the comic strip was more favourably received. The drawing of Sylvie seemed adequately recognisable; people could connect with her. One patient summed this up with the comment 'she could be me'. This patient was clearly able to associate enough with the narrative to allow her to empathise with the character and thus learn from her. This is Gee's (2001) concept of affinity identity in action. Patients and carers in the group particularly associated with Sylvie's intuitive feeling that time was running out and with her need to retain a sense of control to the end. The common issue of diminishing energy was also important to group members, who wished it to be represented in Sylvie's story.

For patients with a terminal illness to make a change, they need to re-imagine their capacity to take fruitful action. In storytelling, the act of re-imagining is not done in isolation but with storyteller and listener acting together to understand more about human agency through telling and listening (Josephsson et al., 2022; Leight, 2002). Mutual bonds can be created through this telling and listening process (Stanley & Hurst, 2011). The purpose of this first comic strip was to get people to make such connections with Sylvie, to see that she was one of them. This was vital if the following strips were to influence people's view of themselves and their ability to effect change. The combination of visuals and the story told by Sylvie herself were designed to bring about this feeling of common humanity. This revised

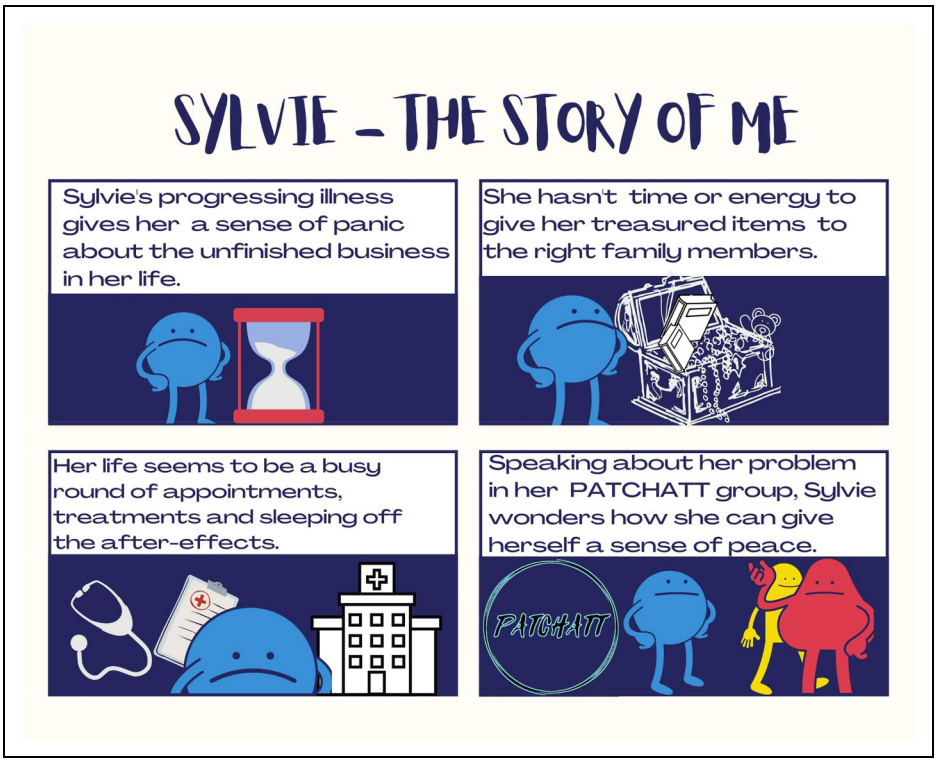

Figure 1. Draft 1 of Sylvie's Story.

version of the comic seemed to adequately serve this purpose.

Having established Sylvie's character and her problem, the PATCHATT group wanted the next comic strip to show how belonging to an empathetic group of people supported Sylvie's ability to make a desired change in her life. The value of storytelling in supporting people to effect change is long-established (VanDeCarr, 2015). Of interest here is stories potential to benefit those living with a life-limiting illness (Frank, 2013). Comics in particular support people to create a world which they retain some control over (McAdams, 1996), with digital comics encouraging readers' social awareness (Shelton, 2014) and championing the right of oppressed voices to speak and be heard (Nayek, 2021). Patient members of the group had a clear vision for the argument the comic strip should make. They wanted it to suggest that belonging to a group gives you access to ideas; that these ideas are not instructions but are there to stimulate thinking and that the agency remains with the individual rather than the collective. The comic strip *Sylvie's plan*, shown in Figure 3 below, sought to satisfy this vision.

Human agency in traditional comics belongs to a superhero, who acts alone to defy the odds and accomplish the impossible. However, *Sylvie's plan* was not a hero narrative of this kind but the tale of a normal human being, attempting to improve her own and others' lives. This is a 'small story' (Georgakopoulou, 2006) which captures Sylvie's experience and the importance of her connections with others. Grassroots comics provided us with a more helpful prototype. Grassroots comics are developed by community groups or non-governmental organisations to tell the story of

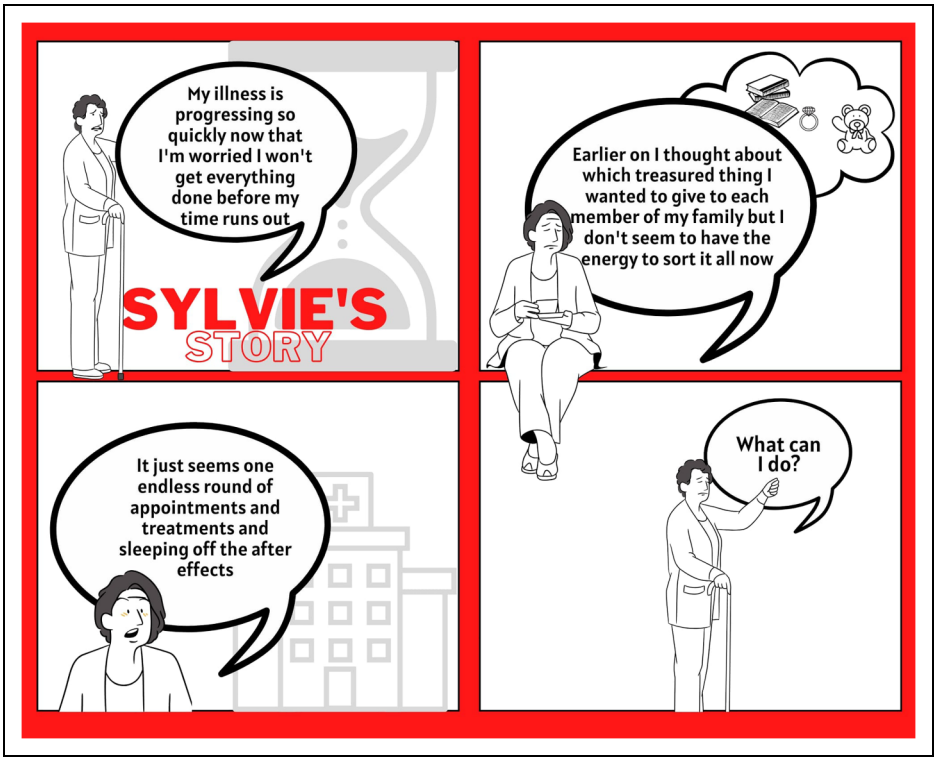

Figure 2. Draft 2 of Sylvie's Story.

specific community issues. They are then posted in public places with the aim of catalysing action (Sharma, 2009). Those who make the comics and their readers are not very different from one another (Sharma, 2009). They are therefore in a good position to evoke a specific response through both the connection and narrative persuasion embedded in the drawings and text (Shelton, 2014).

Sylvie's plan was created with a persuasive mission in mind. It was designed both to send a message about how belonging can support people to act for their own and others' benefit and to sway the reader to apply this message to their own lives (Gavsie, 2019). Sylvie's action as an autonomous individual was of great importance to patients, whose experience supported McCaffrey et al.'s (2016) findings around the positive impact of independence on quality of life. Recognising her autonomy, Sylvie is delighted to get advice which stimulates her thinking. Her decision to act in a certain way is hers alone however. In this instance, belonging does not mean having to speak with one voice. Instead, it supports the strength of an individual to work towards personal goals. Thus, the group support Sylvie both to decide what actions she should take in her unique context and to accept responsibility for the outcomes of her actions, shown in her final comic strip in Figure 4 below.

Sylvie's change acknowledges the difficulties which can come with agency. Other people will not always agree with what you think and what you do. However, it also illustrates the positive impact which sharing our values and beliefs has on our ability to cope with life. It is important that Sylvie shares the results of the action she has taken with the group who supported her to make the change she wanted to

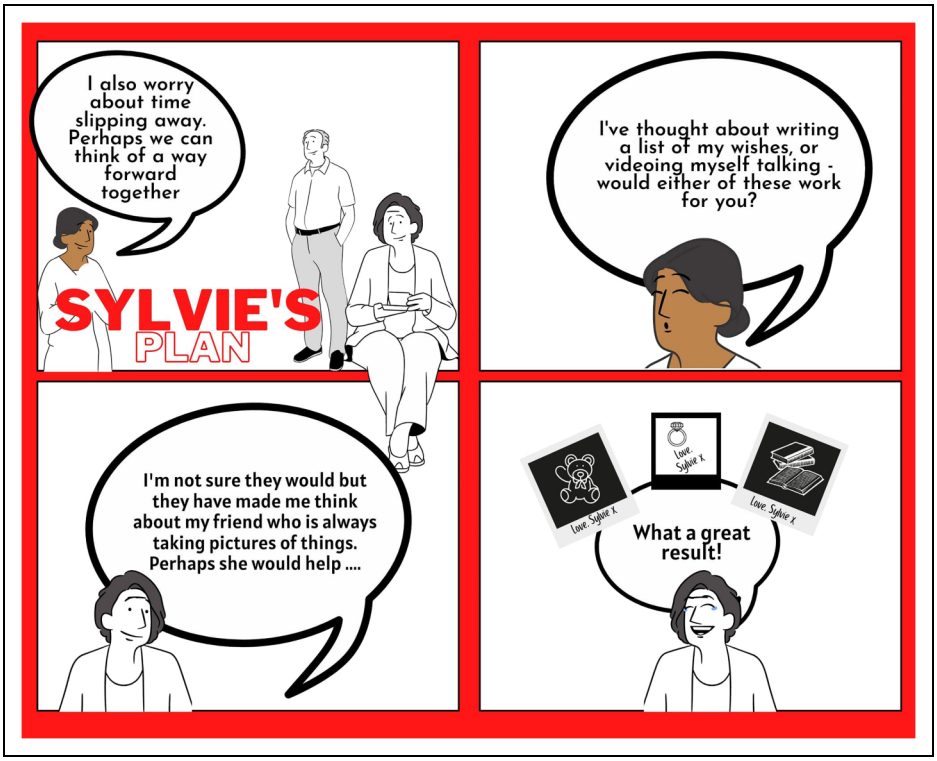

Figure 3. Sylvie's Plan.

see. In so doing, she underlines her affinity with them and her potential to reciprocally support them in realising their own ambitions. The simplicity of the comic form enabled the highlighting of reactions and emotions in a way which would have been more difficult using text alone. The natural divisions provided by the panels allow the reader to focus on one thing at a time and to properly process its implications for Sylvie and, by implication, for themselves.

Discussion

Both the process of developing Sylvie's comic and the final product illustrated the complex interactions between belonging, empathy and agency in the final phase of life. Co-developing Sylvie's comic sparked imagination and connection. It allowed for a joint effort to develop a resource which would stimulate others to be agential. Catalysing people to take action has connotations of social movements. Using storytelling to support such movements is exemplified in Ganz's (2011) public narrative model, where exploring values and thinking innovatively leads to system level change. Patient storytellers are seen as activists who challenge the status quo (Zoller, 2005), lead personal change and set the way for those who follow them (Williamson, 2018). For the PATCHATT development group, this raised questions of the delicate balance between autonomy and collective purpose.

Producing Sylvie's story relied on both individual agency and a clear sense of common purpose. I had assumed that in the final stage of life people may focus on ensuring their own comfort and safety and that this may result in a contained, inward-looking attitude. The importance of retaining autonomy was clearly important to individuals in PATCHATT. However, this was accompanied by a strong sense of collective purpose as we sought to develop effective

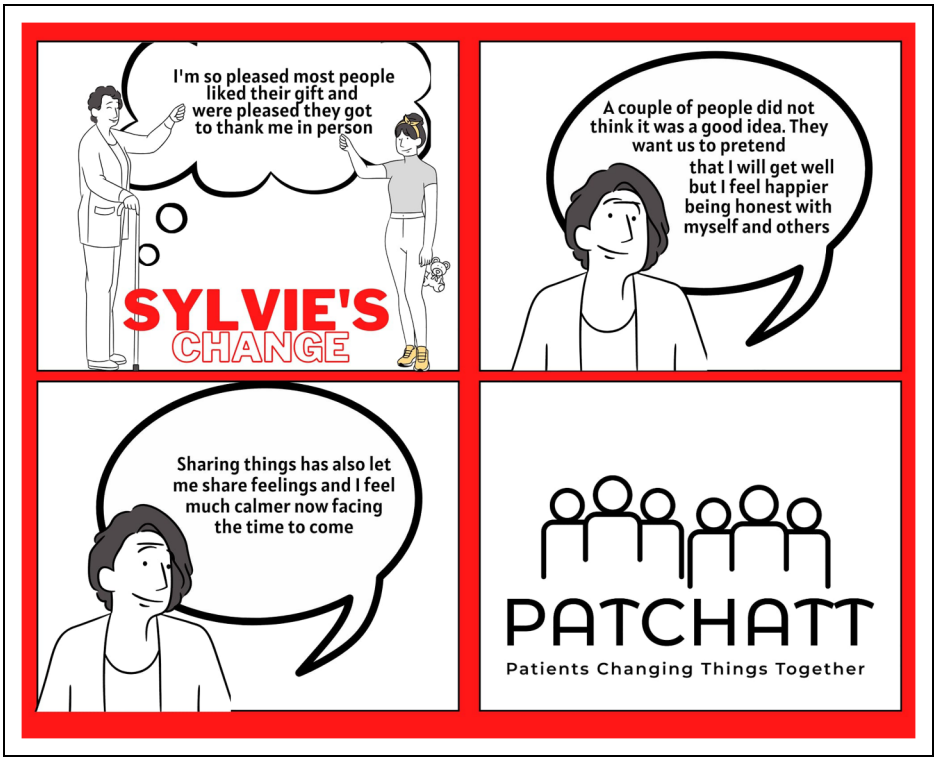

Figure 4. Sylvie's Change.

comics to influence others. Belonging to a group seemed to enable individuals to share their views and take action to change things. Equally, the group drew from the strength of individuals to complete the complex task of producing comics which relied on collaborative thinking and action. Sylvie's comic was in this sense both the product of joint endeavour and a catalyst for it.

Empathy was clearly an important factor in the sense of belonging developed by the PATCHATT group. There is a world of difference between those who have been told by a doctor that their life is finite and those of us who know this as part of the human condition but choose not to really believe or focus on it. However, through our joint work in developing Sylvie's comic, our ability to stand in one another's shoes deepened. We were able to consider together how to craft the comic to elicit the same kind of empathy from the reader, which we hoped would allow them to develop a belief in their own agency, at whatever stage of life they found themselves. Sylvie's comic suggests social groups can support members to broach honest conversations about dying and death in their own lives (Bradley et al., 2023). It also underlines comics' potential to bring about wider social change (McCloud, 2000) through extending this conversation.

Sylvie's story is one of a series of comics we went on to co-create in the PATCHATT group. We recognised that it was not possible tell a single story which would be credible, relevant and inspiring to the wide range of people living with a terminal diagnosis. However, all the comics had the same aim – to stimulate the reader's imagination and allow them to understand the relevance of the comic to their own situation. This sense of belonging may then allow people

with a terminal illness to reconceptualise themselves as active agents in their own future and to use this to catalyse action (Wolk, 2007). Of course, not everyone wants to tell their story publicly. Some members of the PATCHATT development group were more reticent than others. However, commenting on Sylvie's story allowed them to use their experience to feed into the joint development process without overtly revealing the details of their story to others. They could still connect, sometimes through silence, to the group endeavour.

The homogenous nature of the PATCHATT development group could have proved a limitation to this work, reducing the breadth of its potential applications. However, this particular story of comic co-development has been shared in several professional settings. It appears to have an applied relevance to nurses in end-of-life planning discussions and to teachers of children with special needs. We look forward to working with cross-disciplinary colleagues to understand more about the complex intersection between comics, belonging, empathy and agency in diverse contexts.

ORCID iD

Amanda Roberts https://orcid.org/0000-0002-1172-3242

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Author Biography

Amanda Roberts is the co-funder of the PATCHATT Community Group. Her current work focuses on supporting people to acknowledge, talk about and plan for death, dying and grieving.