A two-phase qualitative enquiry into storytelling's potential to support palliative care patient-led change, using a systematic review approach

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Abstract

A terminal diagnosis can diminish an individual's sense of agency and identity. Leading change appears to restore a sense of agential self. The first phase of this literature review explores factors influencing patient-led change across the palliative care ecosystem. The second phase illuminates how storytelling can support palliative care patients in leading ecosystem-wide change. 35 studies were identified in Phase 1 and 36 in Phase 2. This research highlights the need to situate patient leadership activity within a palliative care ecosystem to understand factors likely to support or hinder patient leadership activity within it. The evidence indicates the potential use of storytelling to support patients with a life-limiting illness to lead change across the palliative care ecosystem. This challenges current conceptualisations of such patients and offers them instead as an additional source of palliative care support.

Introduction

I recently volunteered in a hospice day therapy centre. Discussions with patients revealed the disrupted and diminished identity which many felt terminal illness brings (Exley and Letherby, 2001). I use identity here to mean the kind of person one is recognised as being, at a given time and place' (Gee 2001, p.99). Patients also

experienced a decreased sense of agency, the ability to make a difference to one's own life and that of others (Bandura, 1977). They told each other stories of shifting relationships with family and friends and a changed sense of who they were. This went beyond sharing illness narratives, shown to support patients' sense of self (Sakalys, 2003). Here, possible solutions were offered through a mutual commitment to finding a way forward. Patients supported each other to plan for and lead change, helping restore a positive sense of an agential self (Roberts, 2021). Patients wanted to effect both personal and system-wide change. I wondered how such change leadership might be supported.

Bronfenbrenner's (1994) work on ecological models of human development was useful. He suggests that human development occurs through repeated, reciprocal interactions between persons, objects and symbols, referred to as proximal processes, in the human beings' immediate environment, termed an ecosystem. Distributed or shared leadership is increasingly valued in the NHS ecosystem (West et al., 2015). Despite power issues (Martin et al., 2015), cultural clashes (Naylor et al. 2015) and poor understanding of practical applications (Currie and Lockett, 2011), it challenges traditional heroic leadership models and satisfies the call for non-positional, shared approaches (Cordoba et al., 2021). Leadership is here conceptualised as practice (Raelin, 2016) through human interaction (Woods and Roberts, 2018), focused on an individuals' intention to make a difference.

Patient leadership is one facet of distributed leadership. Palliative care policy has long recognised patient and service benefits of user involvement in service development (NCPC/NHS, 2009). The global increase in life expectancy (Government Office for Science, 2016), unaccompanied by increasing levels of good

health (Mathers and Loncar, 2006), has raised its significance. With one in seven people projected to be over 75 by 2040 (Government Office for Science, 2016), a shift to self-management and cross-boundary care is urgent (Stafford et al., 2018). Despite this, there remain infrequent opportunities for individuals with a life limiting illness to contribute significantly to healthcare development. Concerns over appropriate roles (Johnson et al., 2021), the ethics of making demands on the sick (Wohleber et al., 2012), and doubts over patients' ability to think and make choices (Richardson et al., 2010) make them rare partners in co-produced research. Whilst this exemplifies a view of patients as the 'done to', the passive objects of the medical 'gaze' (Foucault, 1973), alternative discourses are emerging. A developing belief in society's responsibility to promote health and prolong life (NHS, 2015), alongside the new public health movement's championing of community participation (Sallnow et al., 2016), lays strong foundations for patient leadership. Some effective practice has been reported: a King's Fund report (2013) showcases clinicians and patients jointly tackling research agendas, enacting principles of inclusivity, power sharing, reciprocity and relationship building (Turner and Beresford, 2005). However, the rejection of demands for the appointment of a chief patient officer to NHS organisation boards (Naylor et al., 2015) illustrates ongoing challenges to securing strategic influence.

Research evidence of successful patient-led change initiatives is limited then, as is an understanding of how to support ecosystem-wide patient-led change. The emergent field of palliative care patient leadership seems to fit Frickel et al.'s (2010) category of ''undone science'', an area left unfunded or ignored by research but which social movements consider worthy of investigation. This two-phase, iterative enquiry moves leadership patient leadership towards 'done science'. The purpose of

the first phase was to explore factors influencing patient-led change across the palliative care ecosystem.   Drawing on findings of the first phase, the second phase sought to illuminate how storytelling can support patients in leading such change.

Methods

Advice on transparently conducting and reporting qualitative syntheses was taken from the PRISMA statement (Page et al., 2021), the PALETTE approach (Zwakman et al., 2018) and the ENTREQ (Tong et al., 2012) and eMERGe (France et al., 2019) guidelines.

Identification of the literature

Relevant studies were identified by:

- Database searches: Phase 1: Embase and PubMed; Phase 2: Scopus, PubMed, Embase and PsycInfo

- Following references from included studies and pearl growing

- Searching Google Scholar

Search strategy

The research strategy employed is detailed in Table 1.

Phase 1: Scoping review Limits: written in English; published 2000 – 2022			
Database	**Date**	**Search no.**	**Search terms**
Embase; PubMed	22.6.22	1	patient AND palliative care AND leadership
		2	patient AND end of life care AND leadership
		3	patient participation AND palliative care
		4	patient-led AND change
Phase 2: systematic review Limits: written in English; published 2000 – 2022			
Database	**Date**	**Search**	**Search terms**

		no.	
Embase; PubMed; Scopus; PsycInfo	2.9.22	1	patient AND palliative care AND storytelling
		2	patient AND palliative care AND narrative
		3	patient AND end of life care AND storytelling
		4	patient AND end of life care AND narrative
		5	palliative care AND storytelling
		6	palliative care AND narrative
		7	patient AND leadership AND storytelling
		8	patient AND change AND storytelling
		9	storytelling AND process

Table 1: Research strategy

Inclusion and exclusion criteria

Cooke et al.'s (2012) SPIDER strategy was used to develop inclusion criteria. In Phase1, reports were included if they adopted a qualitative or mixed-methods methodology and explored barriers to and enablers of patient-led change by adults receiving palliative care or interfacing comparative populations such as geriatrics, adults with multiple long-term conditions and oncology patients. In Phase 2, qualitative or mixed-methods reports were included if they evidenced storytelling elements and processes or how storytelling can support patient-led change. Reports not meeting these criteria were excluded.

Quality assessment

Reports were assessed against Lincoln and Guba's (1985) criteria for evaluating the trustworthiness of a qualitative study - transferability, dependability and confirmability. Mays and Pope's (2000) questions around relevance, clarity, appropriateness of design, systematic nature of data collection and analysis and researcher reflexivity were also drawn upon, together with COREQ qualitative research reporting guidance (Tong et al., 2007).

Data analysis and synthesis

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Themes were derived through an inductive response to the data which revealed repeated patterns of meaning (Braun and Clarke, 2022). Data were tabulated and annotated with concept codes. A narrative synthesis approach, a proven technique in the evaluation of public health interventions (Achana et al., 2014), was then used.

Results

Phase 1

35 relevant reports were retrieved (Figure 1).
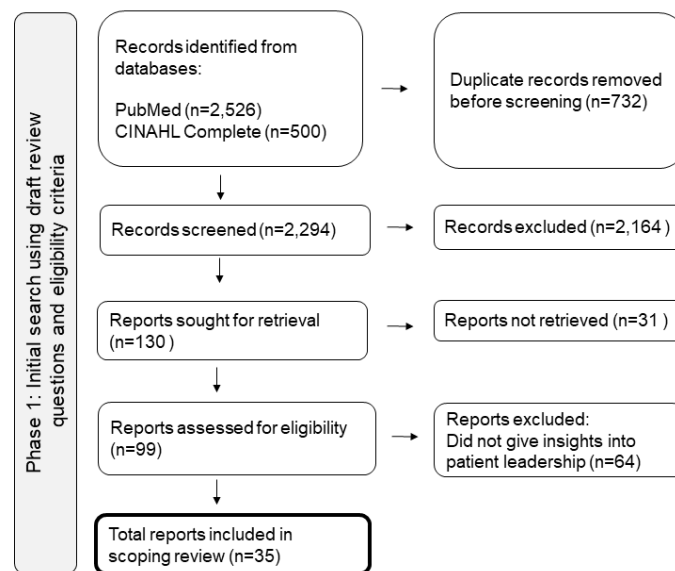
Figure 1: Reports retrieved for Phase 1 scoping review

Table 2 summarises reports included in the review.

INSERT TABLE 2 HERE

Table 2: Summary of reports included in Phase 1 scoping review

Following Popay et al,. (2006) I used a Bronfenbrenner-based (1994) palliative care ecosystem model as an organising device for a thematic analysis of reports' findings. Whilst factors may apply across several levels, assigning them to the level of apparent strongest influence produced a useful map (Figure 2).
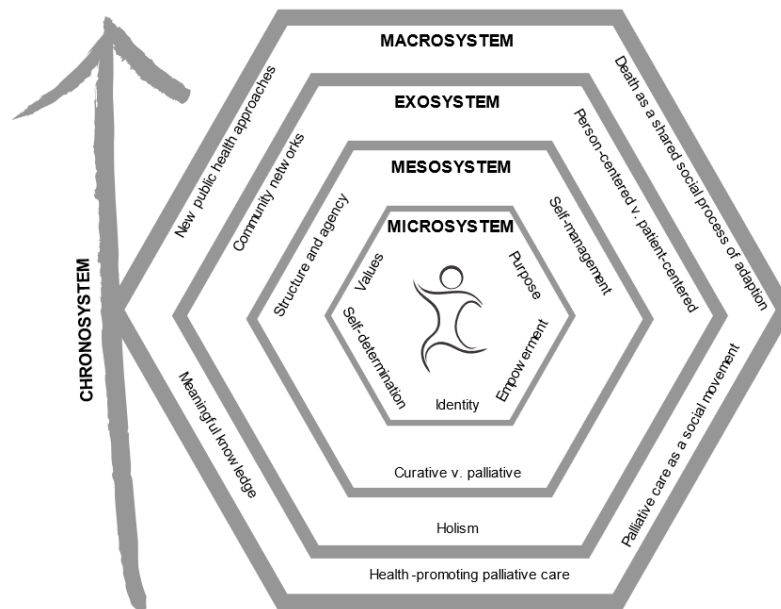
Figure 2: A map of the palliative care ecosystem, annotated with key factors influencing patient-led change

This map was used to guide an analysis of the main themes arising at each level.

Meaning-making within the microsystem

The theme of meaning-making dominated reports exploring the palliative care microsystem, that is, the patient's home environment. Meaning-making often begins with values clarification (Olsen et al., 2020). Exercising a sense of control over identity at the end of life (Wakefield et al., 2018), often manifested as a determination to be seen as person first, patient second (Chatland et al., 2021; Epstein et al., 2019) is reported as a dominant value. The resultant sense of empowerment (Buckley 2002; Chambers et al., 2019; Collins et al., 2015) arises from many sources

including changing the narrative around death. Here, understanding the end of life as a time of choice and entitlement (Omilion-Hodges and Swords, 2017) for an autonomous individual (Kuosmanen et al., 2020) challenges common conceptualisations of death as merely loss.

Meaning can also be made through converting self-determination into activity (Lethborg et al., 2012; Mackin et al., 2009; Sahlberg-Blom, 2000). Here, acting in accordance with their values and goals, patients seek to give something back (Sargeant et al., 2007) through improving care for others (Vlckova et al., 2021; Terry et al., 2006) or supporting those in a similar situation (Von Post and Wagman, 2019), both effected through peer connection (Sawyer et al. 2021; Cartmell and Coles 2000).

Problematising patient agency within the mesosystem
Within the broader context of the mesosystem, which includes healthcare organisations outside of the home, patient autonomy is conceived as self-management (Davidson et al., 2012). Conceptualising patients as active agents allows them, for example, to problem-solve alongside clinicians (Davidson et al., 2012). Acknowledging patient agency as situated within social and organisational structures points towards its complexity in action, however. Giddens (1984) argues for the complementary nature of structure and agency, with humans drawing on structures to act, and, through acting, impacting on them. However, others see them as oppositional, with societal structures blocking individuals from taking desired action (Morrin et al., 2008). This is exemplified in dominant medical mores' stifling of patient leadership through the potential clash between curative and palliative understandings of end-of-life care (Omilion-Hodges and Swords, 2017).

Maintaining a person-centred approach within the exosystem

The exosystem provides an extended context for personal development, such as healthcare settings which the patient may or may not be a part of. Whilst individual agendas are challenged in the exosystem (Olsen et al., 2020), person-centred care situates the individual as leader of their life project (Olsen et al., 2020), rather than nominal contributor to external plans (Brighton et al., 2018). Networking empowers individuals to face system-level challenge, through camaraderie, solidarity and acceptance (Cotterrel et al, 2010). Fostering such networks allows a holistic approach to palliative care (Sawyer et al., 2021), with patients taking a leading role in addressing physical, social, spiritual and psychological needs (Buckley, 2002).

Understanding death as a social phenomenon within the macrosystem

The macrosystem is the dominant pattern of belief systems, customs and life-course options which impact on a patient's potential for development. Learning with and through others is recognised as key to both living and dying well, supporting our humanity and individuality (Hakanson et al., 2012). Here, alternative conceptualisations of death and dying challenge the dominance of the biomedical perspective, with hierarchical ways of knowing contested by meaningful knowledge produced through community learning (Sawyer et al., 2021). Acknowledging death's inevitability (Hakanson et al., 2012; Daveson et al., 2015) allows its reconceptualisation as a shared social process (Sawyer et al. 2021), with patients and health professionals working collaboratively to maximize quality of life and death (Cook and Bergeron, 2020). Within the social movements of a new public health framework, health-promoting strategies such as individual, community and service-

level partnerships catalyse cultural and philosophical re-imaginings of patient empowerment, autonomy and dying (Sawyer et al. 2021; Stajduhar et al. 2010).

A rationale for Phase 2

Bronfenbrenner (1994:38) argues that a process-person-context research model is needed to investigate his propositions regarding human development. Whilst the Phase 1 scoping review looked at person and context, it did not investigate the nature of the proximal processes – the interactions between human and human, human and environment – which would catalyse individuals' development as leaders of change. Storytelling was mentioned as a catalyst for such processes in several Phase 1 reports (Lethborg et al., 2012; Neville et al., 2020; Omilion-Hodges and Swords, 2017; Sawyer et al., 2021; Terry et al., 2006). The term 'story' describes an organised account of events and experiences, designed to convey a particular meaning (Anglin et al., 2022). Phase 2 explored how storytelling might enable the activity of patient-led change.

Phase 2

36 relevant reports were retrieved through the systematic search process (Figure 3).
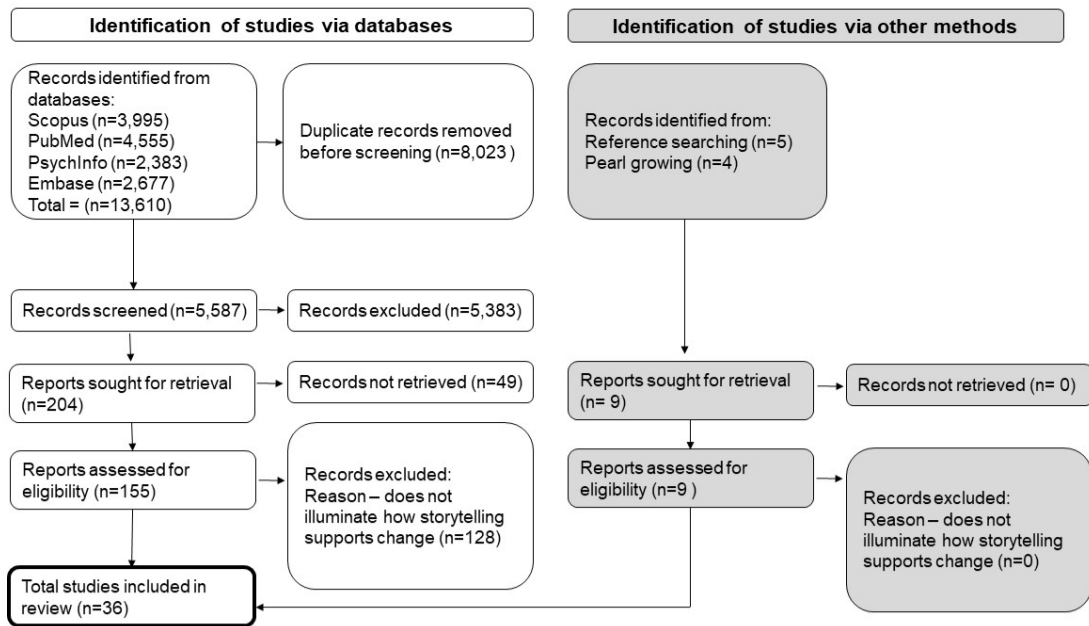
Figure 3: Flow chart showing study selection based on revised PRISMA statement (Page et al., 2021a)

Table 3 summarises reports included in the review.

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Table 3: Summary of reports included in Phase 2 systematic review

Renewing an individual's sense of self and agency

Specific story types challenge restitution narratives, where people get ill, get treatment and recover, and chaos narratives, where no one gets better and life falls apart. These quest narratives offer the sick person a distinctive voice and the potential for action (Frank, 2013). Here, people meet suffering head on and use it proactively. In these 'hero's journey' stories (Elshafi et al., 2018), the hero is propelled from a familiar context into a new one by a call to adventure. They return transformed, with new knowledge about themselves and the world (Lamprell and Braithwaite, 2016). The traditional hero-villain-victim story triangle (De Meyer et al., 2021), mirrored by the doctor-illness-patient healthcare triangle, is challenged by in story of patient agency and activity.

Stories thus give meaning to the illness experience, allowing the teller to use their unique story to change its impact (Alawafi et al., 2021; Gucciardi et al., 2021). They motivate individuals to turn intention into action (Byrne and Soundy, 2019), supporting the development of agency and self-efficacy (Southall et al. 2007; de Meyer et al. 2021). Bruner (2002:65) summarises this succinctly – 'self-making is a narrative art'. Here, storytelling allows the teller to challenge assumptions and re-story a life (Mancini, 2019; McLean et al., 2007), with stories both enabling the imagining of other worlds and supporting the teller in actively working towards them (González-Monteagudo, 2011; Mourik et al., 2021; McLean et al., 2007). Patients who lead change seek to bring such other worlds into being through making a difference to something which matters to them. Here, unexpected new developments such as recurring illness can be integrated into the present world view (Bietti et al., 2019), supporting planning (Anglin et al., 2022) and action.

Catalysing action

Stories can also encourage involvement in more far-reaching ecosystem change. These tales, seeking to catalyse listeners into specific action (Abma and Widdershoven, 2005), can be told through words, images and sounds (Haigh and Hardy, 2011). These are Goodchild et al.'s (2017) persuasive stories, which inspire us to see differently, feel empathy and overcome conflict, support inclusion and participation and set collective agendas for local policy action (Mourik et al., 2021). Common characteristics of persuasive stories such as protagonist and antagonist, focus on space and time, issues to be overcome (Anglin et al., 2022; Elshafi et al., 2018) and a link to the teller's cultural reality (Byne et al. 2019) make such stories powerful recruiters, particularly if using data in a captivating way (Lee et al., 2015). Stories seeking to change policy are further strengthened by a specific context, causally-related events, archetypal characters of heroes, villains and victims and a concluding moral (Beck, 2018).

Counter stories which challenge current norms and practices (Abma, 2003) are particularly important in understanding patient leadership. Challenges to individual or societal ways of seeing (Bietti et al., 2019; Essebo, 2022; Mourik et al., 2021; Schedlitzki et al., 2015) support the equalisation of power. Thus, individual patients' values and goals can drive a narrative (Young and Rodriguez, 2006) or allow groups to scope out alternative ways forward (Black et al., 2022; Quaid et al., 2010). Storytelling is thus accepted as a key policy-influencing strategy (Fadlallah, 2019), catalysing changes in group practice (Campion-Smith et al., 2011) and creating rather than reporting change (Essebo, 2022).

Establishing a relational approach to change

For Ricoeur (1984), storytelling is not a private cognitive activity but a reciprocal interpretive social process including action and reaction. Its strength as a leadership activity comes from its capacity to enable a connection between storyteller and listener, creating a relational experience through speaking, listening and responding (Shapiro, 1993, in Sakalys, 2003).

Understanding storytelling as a reciprocal, active, inventive process shows its potential for effecting change across the palliative care ecosystem (Alawafi et al., 2021). For patients with a life-limiting illness, making a change involves re-imagining their capacity to take impactful action. Re-imagining is often a reciprocal act, with teller and listener re-negotiating understandings of human agency as stories are told and re-told (Leight, 2002; Josephsson et al., 2022). Abma and Widdershoven's (2005) view of stories as socially situated language performances extends this point. Here, meaning is constructed through a dialogic process where teller and listener engage with the story and with one another, creating mutual bonds (Stanley and Hurst, 2011).

This proposition challenges received wisdom on the importance of rational arguments and metrics in change-making (Fancott, 2016). Instead, it is suggested that the emotional or intuitive elements stories bring are needed to convince us at a deeper, tacit level of the value of an argument (Sole and Wilson in Mourik et al., 2021; Hineline, 2018). Here, the storyteller's authenticity and moral imperative is crucial (Gruber, 2007; Fancott ,2016). Bruner (1986) confirms storytelling as an alternative to logio-scientific arguments, proposing that narrative seeks to convince us of lifelikeness, whilst argument seeks to sell us only one truth. The search for

universal truths is thus juxtaposed with the search for ongoing connections which extend understanding.

Critical discussion and conclusions

This research brings into sharp focus the need to situate patient leadership activity within a palliative care ecosystem to understand factors likely to support or hinder patient leadership activity within it.   Whilst this is designed as a theoretical piece, some consideration is therefore given below to how elements of this ecosystem might influence the operationalising of patient leadership activity. Phase 1 demonstrated how the elements making up the ecosystem – its organisations, systems and ways of thinking (Bronfenbrenner, 1994) – offer potential challenges to patient leadership. The dominance of current ways of being, seeing and knowing can militate against patient-led change. The sense of purpose shown by patients with a pressing change agenda, coupled with the resilience inspired by their reclamation of the dying discourse, appear to support partnership rather than an adversarial stance. However, a consideration of system influence in other change models may lead to alternative conclusions.

Change models focusing directly on patient leadership are scarce and broader healthcare system change theories do not fully explore system influence (see, for example, NHS, 2018; NHS, 2019; National Palliative and End of Life Care Partnership, 2021). This is perhaps to be expected of service-generated theories. Social movements in health have more to offer here. Drawing on community or people power to drive forward change in healthcare provision (del Castillo, 2016), such movements take greater account of context. The compassionate communities' movement, for example, highlights naturally occurring circles of care around a sick person (Abel, 2018), with community support networks and formal healthcare

systems working collaboratively to provide support. Compassionate communities'

success (Abel, 2018) confirms the possibility of the collaborative, cross-system

working needed for patient leadership. However, the centrality of patient agency

differentiates it from compassionate communities, suggesting the need for an

alternative change model. The theory of figured worlds has some explanatory value

here.   Figured worlds are imaginary realms in which we can embrace new frames of

understanding, where identities can be formed and transformed (Holland et al.,

1998). The importance of stories in effecting such transformation is exemplified in

the self-help group Alcoholics Anonymous (AA). Here, groups of men and women

tell personal stories through which they identify themselves as alcoholics. In so

doing, they open up the possibility of behaving differently within this identity – of not

drinking – and therefore of making a new identity. Their personal narratives can both

reveal new understandings to the teller and act as texts which listeners can

reinterpret (Steffen, 1997).

Understanding the identity-making properties of storytelling in figured worlds

underlines the importance of the reciprocal nature of storytelling. Following the

example of AA storytellers, in operationalising leadership activity patients could work

with peers to modify their self-perception as a sick person or burden and re-imagine

themselves as assets, as leaders of change. Such reinvention could result in action,

the leadership of activities which bring about the change they seek. The

investigation of storytelling in Phase 2 illuminated how this proximal process might

support patient-led change.

The diminishment of self-view caused by illness can lead to a weakening ability to

take charge of one's own life and control passing to family or clinicians. Some sense

of agency can be re-established through authentic storytelling, exploring values,

what matters to the individual at this life stage (Olsen et al., 2020). Storytelling in the microsystem can support this self-exploration process, re-establishing the teller's command over their life through controlling the listener's focus (Anglin et al., 2022). Self-view can be enhanced, empowering the storyteller to change their narrative around illness and death (Chambers et al., 2019) and illuminating what needs to be done to bring about their reimagined world (Mourik et al., 2021).

The process of learning to tell an authentic story is key to AA's theory of change. New members listen to the stories of older members. Their connection with these narratives enables them to craft and recount their own stories, to which others listen, within a mutually supportive community of practice. Lave and Wenger (1991) describe communities of practice as a set of social relations between people, activities and contexts which support newcomers to become full participants. The concept of legitimate peripheral participation explains how experienced colleagues - 'adepts' - provide access to practice which supports the development of 'apprentices'' practice and relationship-building, leading to potential identity development. Drawing on this model, peer support in the microsystem could allow individuals to hone their stories, in readiness to use them to stimulate change at other, potentially less receptive, ecosystem levels. The individual, as leader of their own story, sows the seeds of patient leadership.

Patients seeking to lead change within the mesosytem are challenged both by their self-view and the views of others. Stories can be used to combat the potential challenge to individual agency structures and norms offer. Patients are reconceptualised from informants on pre-set organisational agendas to authentic knowledge creators and intentional leaders (Bhaksar, 2010). An imperative for

change (Ricoeur, 1984) or an unexpected turn of events (Bruner, 2002) can be the catalyst for such action (Abma and Widdershoven, 2005), where accepted ways of doing and being are tested and new meaning is made through a reciprocal process of teller and listener engagement (Stanley and Hurst, 2011).

The challenges of patient leadership increase in the exosystem. Here, patients may seek to influence wider health networks where they do not have direct membership. The move towards person-centered care at this level theoretically supports patient leadership, yet organisational agendas can still dominate (Olsen et al., 2020). Patient leaders challenge this dominance, repositioning themselves as active agents (De Meyer et al., 2021), setting their own agenda for change and taking action to secure it.

The conceptualisation of patient leadership as a social movement in health is supported through narratives which seek to persuade, generate consensus for action and set collective change agendas (Goodchild et al., 2017). This approach is exemplified by Ganz's (2011) public narrative model where an exploration of values and a view of what might be leads to system level change. Patient storytellers are positioned as activists, challenging the status quo (Zoller, 2005) and leading change for themselves and those who follow them (Williamson, 2018). In their stories, emotional and intuitive impact trumps metrics-based evidence (Hineline, 2018). Despite the potential association of health activism with conflict, stories here value and promote shared leadership for mutual gain (West et al., 2015). The service ecosystems' approach to service redesign provides a helpful theoretical model of such connectivity. Challenging linear processes of service design, service ecosystems offer an iterative approach which takes account of the dynamic,

collaborative, multi-actor nature of change within complex systems (Vink et al., 2021). Here, the institutional rules, norms, meanings and beliefs which enable and constrain change (Vargo and Lusch, 2016) can be reconfigured by actors through questioning what is of value and how the system provides it (Koskela-Huotari et al., 2016). Thus, apprentices might build on or question the experience of adepts; equally, patients might build on or question the experience of healthcare professionals, leading to the potential for widespread change.

The pattern of beliefs and life-course options which makes up the macrosystem can be particularly resistant to change. Storytelling's aim of convincing us of lifelikeness, rather than of one immutable truth (Bruner, 1986) renders it an effective changemaking tool. Here, patients' counter stories challenge current norms and practices (Abma, 2003). Effective, contextually specific stories draw on several story forms to achieve this end. Intentional, collaborative leadership practice (Raelin, 2016) is used by patients to secure elusive change in 'the reasons, intentions and plans of human beings' (Bhaskar, 2010:62).

Vink et al. (2021) emphasise the role of reflexivity in this questioning process. I use reflexivity to mean the self-awareness through which we critique our natural interpretation of life (Siraj-Blatchford and Siraj-Blatchford, 1997). This research suggests stories are key to the reflexive process, allowing people to ask, how might others see this differently and does life have to be this way? (Bruner, 2002). Echoing figured worlds, reflexivity allows the questioning of current ways of thinking and practice and imagining of an alternative future which precedes systems change (Saltmarshe, 2018). The telling of authentic and change-making stories rests on such reflexivity.

Limitations of this research

Within the systematic review approach, my research framing may have led to the exclusion of relevant studies. Searching was equally limited by the reports available and my own technical skills. The tiny proportion of reviewed reports proving relevant suggests some flaws in the search approach. The focus on qualitative studies excluded potentially illuminating studies. It could also be argued that the data presented are necessarily limited by the systematic approach to finding relevant texts. There may, for example, be relevant ideas in cross-disciplinary texts not accessed by the search criteria used. These limitations could be avoided by myself or others in future research, based on the learning accrued from this experience.

Data analysis was undoubtedly affected by my own beliefs and values. I am currently working with a group of patients and volunteers to develop a patient-led change support programme. Responding to Macbeth's (2001) questions on emotional investment, this may mean that I am predisposed to foreground data which is supportive of patient leadership. An alternative interpretation might conclude that, whilst patients are capable of leading change, the structural challenges could prove insurmountable to those with limited energy, time and resources. Concerns over the potential undermining of professional or managerial power which patient leadership implies may need to be addressed to allow story's transformational power.

I used the ecosystem map presented in Figure 2 as an organising framework for my thinking and discussion. However, a systems approach would reject a stratified presentation of the palliative care ecosystem in favour of a fluid and integrated arrangement of interacting variables (Damshroeder et al., 2019). As an event within

a system released from artificial boundaries, stories can form dynamic relationships with change-influencing factors across the palliative care ecosystem. Stacey's (1995) work on complex adaptive systems supports this view. To know the effect of combining one variable with another presupposes a relational predictability and stability challenged by Stacey. Instead, systems are understood to move between predictability and unpredictability, in response to system agents, in this case, storytellers. The potential impact of interaction between story, teller, listener and ecosystem is complicated by this re-conceptualisation.

Data presented in the included reports may have been affected by the original authors' biases. My work as a single researcher exacerbated this issue. The robust research processes described in this report have lessened but not removed bias. However, an analysis of the 'plausibility' of my data synthesis (Howell Major and Savin-Baden, 2010:114) remains positive, with the potential weaknesses of my research reflected in the tentative nature of my conclusions reached.

Suggestions for future research

The need to develop community-based palliative care interventions to fulfil the expected growing demand for palliative care is well-established (Government Office for Science, 2016). This review highlights the apparent benefits of using storytelling to support patients with a life-limiting illness to contribute to fulfilling this demand through leading change.   The development of patients as change agents draws upon the interaction between the developing person, the environment and the developmental outcomes sought. To strategise for change, patients need therefore to understand both the complexity of the ecosystem in which change is sought and their capacity to influence it. This research raises fundamental issues about how we understand the potential for human development and the societal contribution of

those approaching the end of life. It does not, however, consider the practical issues such as how to offer this opportunity to a broad spectrum of patients. It is therefore critical that further research is undertaken to explore the leadership capacity of patients with a terminal diagnosis and what practices might support their development as strategic storytellers.

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