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ACCESSIBILITY AND ADVOCACY IN HEALTH HUMANITIES

Susan Levy

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Introduction

The landscape of health and social care is being transformed to address the growing complexity and multilayered nature of health. Within this evolving arena of practice, the arts are becoming increasingly visible and fundamental. Embedding access to the arts and humanities within the context of health and social care requires radical new perspectives, innovative ways of working, and the unsettling of established modes of professional practice. Health humanities is situated within this new landscape of health and social care and is exposing the logic of aligning a social lens alongside the prevailing medical paradigm within health. Practitioners have a key role in supporting the genesis of these new ways of working, namely, by advocating for the use of creative methodologies to enable patient narratives to be integral to patient care, and advocating for access to arts-based activities.

The use of the arts in the helping professions has a long history (Bartoli, 2013). Poetry, painting, creative writing, dance, music, and other art forms have been used as therapy, a form of communication, and a means of self-expression. The impact of involvement in the arts within health is situated at the nexus of where the arts and humanities connect with us at a human, social, and emotional level. This level of connection is contextualized in conceiving of art within health and social care as a process, an experience, and relationship (Dewey, 1934), where the "doing" of art leads to meaningful outcomes (Lloyd, 2015). Conceptualizing of art as an experience brings to the fore the importance of relationships, the patient–practitioner relationship, and the role of advocacy and access embedded within that relationship.

This chapter focuses on two key aspects that are essential to the successful integration of the arts into health—access and advocacy—and the role of practitioners in facilitating for both. First, advocacy and the patient voice are explored through the prism of the patient–practitioner relationship. The use of creative approaches is highlighted as a conduit to new ways of communicating and accessing the subjective worlds of patients. Second, the role of advocacy shifts to practitioners mediating and supporting access for patients to arts and humanities activities through social prescribing. The final section of the chapter addresses the need for caution in applying a creative discourse in practice.

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Advocacy and accessing patients' voices

Health humanities connect the arts to the social dimensions of health and well-being, to empowering and giving voice to patients through positioning them at the nucleus of their care, which can be actualized through advocacy. As Garden (2015: 77) writes, the "health humanities are in essence a form of advocacy," and a means to represent the under-represented: to give voice to the unknown, to new perspectives that are personal and individual, to expose and make visible the complexity and intersectionality of patients' lives (Kumagai, 2008). For Squier (2007), health and social care practitioners can only know, and therefore represent, patients if they are able and willing to situate them within intersectional identities and their broader sociocultural context. An openness to listen and engage with new narratives, new knowledge, and new ways of seeing and experiencing the world is the foundation for making the social dimensions of people's lives relevant within health care and for enabling advocacy to flourish. This rich tapestry of narratives should be framed by a strengths-based approach (Saleeby, 2012) that celebrates and centers patients' capabilities alongside the differential impact that disability, illness, and health have on everyday lives.

Person-centered practice brings to the fore the voice, the experience, and the ambitions of patients within health care. Balancing the prevailing medical discourse alongside the narratives of patients, while a catalyst for change, is not unproblematic. The health and social care professions are turning to the arts and humanities to help expand the parameters of their understanding of patients' lives, and to see things from patients' perspectives. This paradigm shift requires extending the medical frame of vision to be inclusive of other knowledges and other voices (patients, service users, and carers), voices that for too long have been marginalized within health. The use of the arts and humanities in health and social care is beginning to unlock these voices. Access to the arts is opening innovative ways for patients to express themselves and to communicate with their practitioners. From using images to using their bodies, "the geography closest in" (Rich, 1986: 212), patients' lives are embodied through the arts. These developments are stimulating change and redefining the health and social care discourse (Crawford et al., 2015; Huss and Bos, 2018; Levy, 2018).

Let us consider what this might look like in practice, through a scenario of a health practitioner empowering their patients to advocate and (re)present themselves in their day-to-day life. The creative use of Photovoice (Capous-Desyllas and Bromfield, 2018) enables the practitioner to ask a patient, who would benefit from being more physically active, to take a photo of their daily walk or exercise. The photos provide an insight into the sociocultural aspects of the patient's life alongside their physical activity. The photos enable the patient to creatively (re)present themselves to their health practitioner and open a dialogue for reflective discussion. At the core of this simple and achievable example is a relationship between patient and practitioner: here, both have a voice and knowledge to contribute to identifying and achieving health outcomes. This scenario visualizes art as advocacy, enacted through practitioners integrating creative methodologies into the patient–practitioner relationship.

Creative approaches open a space for reimagining the relational dynamic that occurs between patients and practitioners (Atkinson et al., 2015). The emerging relationships that develop through this process are built on trust and are fluid, providing for reciprocal learning and unlearning, for knowing and unknowing. Advocacy emerges here through practitioners having the confidence, knowledge, and "permission" (Levy and Young, 2018) to work in new and innovative ways.

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Social prescribing: advocating for access to the arts

Arts prescribing is a form of social prescribing that refers specifically to advocating for involvement in arts activities (Stickley and Eades, 2013; Stickley and Hui, 2012). Social prescribing involves health and social care practitioners working collaboratively with patients to identify and advocate for involvement in community-based activities, including the arts. (The generic term *social prescribing* is used in this chapter.) Social prescribing complements, and for some patients replaces, traditional medical interventions to enhance overall well-being and reduce hospital admissions, thus creating new possibilities for reimagining health prescribing. It is being used across the spectrum of medical and social dimensions of health, for conditions including Parkinson's (McGill et al., 2018), in mental health (Sapouna and Pamer, 2016), and in survivors of domestic violence (Gray and Schubert, 2010), through to patients who are marginalized and isolated (Loftus et al., 2017). It has been found to support the development of social capital (Bourdieu, 1986) and to address some of the underlying social determinants of health inequalities (Mani, 2017; Morton et al., 2015). Outcomes from prescribing involvement in arts-based activities coalesce around meaningful relationships, a sense of belonging, confidence, and overall well-being; "it is the quality of the human relationships and the atmosphere that is created by the service providers that was of most significance to the participants" (Stickley and Hui, 2012: 578).

The first UK survey of general practitioners' views on social prescribing and the use of arts in health care was launched in 2018 (Aesop, 2018). The findings reveal 66% of respondents in agreement that the arts could make a positive contribution to improving health and well-being. A key challenge and opportunity for general practitioners and other health professionals to translate this vision into reality is around access: access in relation to the availability of arts and humanities activities that are accessible (physically, socially, culturally. and economically); access to information about the availability of activities to signpost patients (Alliance-Scotland, 2016); and access to collaborative working between health, social care/social work and arts-based practitioners to share knowledge and co-produce meaningful outcomes. Throughout this chapter references to health care have intentionally been broadened to health and social care/social work. This is an acknowledgement of the need for collaborative working to achieve the ambitions of the arts contributing to health and well-being outcomes through social workers/social care practitioners facilitating access to community arts-based activities.

The following four points act as scaffolding to frame, guide, and support advocating for and mediating access to the arts as a conduit for transforming future health and social care:

1. *Knowledge-based advocacy*
    - Development of a comprehensive evidence base concerning the impact of the arts in health and social care, to support decision-making in advocating access to creative practices.
2. *Accessible arts*
    - Development of accessible, sustainable, and inclusive arts and humanities activities that can accommodate a diversity of health and social care needs.
3. *Accessible information*
    - Access for patients and health care and social care practitioners to relevant and current information on the availability and accessibility of arts and humanities-based activities.

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4. *Integrated working*

    - Effective collaborative working between patients and health-care, social care, and arts-based practitioners sharing different knowledges to co-produce health and well-being outcomes.

Creativity in policy and practice

The integration of arts and humanities into health and social care is occurring in parallel to a policy discourse around creativity. At a time of prevailing neoliberalism, austerity, and limited budgets, health and social care practitioners are tasked with being more innovative and creative in their practice. "The professional and the supported person should develop creative solutions to meet the outcomes identified in the support plan" (Scottish Government, 2013). Creative practice, if used uncritically, may achieve economic rationalization, but may fail to connect with the art, the emotional, relational, and affective aspects of creativity. As Negus and Pickering (2000: 260) have noted, creativity risks being a "dominant category, but a residual concept." Caution should thus be exercised in supporting greater access to creative practice that could inhibit "the articulation of crucial advocacy arguments" (Madden and Bloom, 2004:134; 2001) and enabling patients to (re)present themselves. The rationale for creativity in practice must retain a focus on advocating for and mediating access to activities that can stimulate aesthetic affect and change in patients' lives. Furthermore, the essence of creative freedom should not be stifled or suppressed through the assimilation of the arts into health care or the "ineffable character of arts . . . lost in clinical service provision" (Broderick, 2011: 106). Strategic planning and policy development around the integration of arts into health care must be advocated through a united voice, that is, a voice that reflects and retains the unique attributes of each discipline: the arts, health care, and social care.

Conclusion

Health humanities offer a contemporary lens for advocating for change in the delivery and experience of health and social care. There is a natural synergy between health, social care, and the arts that practitioners can use as they integrate the social dimensions of health alongside or in place of traditional medical perspectives. The integration of the arts into health and social care practice has led to health narratives being diversified and inclusive of patient voices. These ambitions are being achieved through practitioners working more creatively, using arts-based methodologies in their practice to advocate for patients to (re)present themselves in context; and through social prescribing, advocating, and mediating access to arts and humanities activities. Further work is required to ensure these developments become sustainable, visible, and accessible; and that advocacy for the arts is sustained as a fundamental driver in the evolving landscape of health and social care.

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