Insider action research in palliative care – the challenges of implementing digital health in a hospice organisation in the UK

Mark Howard

Abstract: This paper describes the first-person experience of being a medical consultant and novice action researcher in a UK hospice setting. A new digital IT system resulted in unexpected changes to productivity. An action research methodology using cycles of co-operative inquiry with hospice staff was chosen to investigate. The new technology caused fears among hospice nurses that the authenticity of the hospice ethos would be lost. The hospice staff were concerned about the loss of their role and identity. Action cycles were used to positively transform the hospice nursing structure and admission process.

Keywords: insider action research, palliative care, digital health, identity

1. Introduction

This paper aims to describe the endeavours of a novice action researcher in a healthcare environment. A period of staff upheaval and conflict arose after the introduction of a digital
patient record into the inpatient unit of a hospice. The nursing staff found their workload increase, and the digital system limited their ability to admit patients to the ward. Through action, reflection, and learning, the hospice team explored this paradoxical reduction in organisational efficiency that the technology brought to their working lives and how it affected their perception of their role. It allowed the frontline staff a voice and communicative space so senior management could understand the unintended consequences of information technology (IT) investment.

Throughout the project, the inquiry group’s perception of technology changed. Instead of being seen as a novel solution to improve efficiency, they recognised it as a significant factor in the crisis. The creation of the communicative space allowed the co-participants to express their voice and challenge the structures of power that wished to modernise hospice practices using technology. It enabled them to have agency in how they shifted their working practices to account for the technology and bring back the sense of identity in their role as hospice nurses.

Action research has been implemented in palliative care to bring about change and gain knowledge from practice (Hemberg & Bergdahl, 2020; Hockley & Froggatt, 2006; Hynes et al., 2012b; Jack et al., 2009; Kaiser et al., 2019; Molloy & Phelan, 2022). It recognises that participants have a say in how learning is gained about them and the decisions that may affect them. It is intensely political and requires the practitioner-researcher to understand the organisation’s power structure and politics.

The World Health Organisation defines palliative care as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual” (World Health Organisation, n.d.). Although this definition is accepted, in a health organisation, several views about a particular operational problem or process exist. On the other hand, according to Bradbury (2015), action research is “a democratic and participative orientation to knowledge creation. It brings together action and reflection, theory and practice, in the pursuit of practical solutions to issues of pressing concern. Action research is a pragmatic co-creation of knowing with, not about, people.”

Action research lies within the critical social theory paradigm and differs from the ontological standpoint of positivism (Hockley, 2012). The researcher does not study the issue through their lens; rather, the problem is studied with other participants in a process of joint meaning-making. Coghlan (2019) argues that

“action research focuses on simultaneous action and research in a collaborative manner.”

and describes how researchers can move between theory and practical knowing (the concept of “interiority”). Action research includes a self-knowledge process, allowing one to reflect and critique one’s insights. A spiral of action research cycles (action, learning and reflection) guide the project. Reflexivity is a crucial feature of participatory action research and involves examining one’s existing ways of thinking, assumptions and underlying patterns of values and worldviews (Kjellström & Mitchell, 2019). An action research approach was used because of the participative principles that lie at its core and to bridge the gap between theory and practice.