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THEORETICAL STUDIES

Making the invisible more visible: Reflections on practice-based humanising lifeworld-led research – existential opportunities for supporting dignity, compassion and wellbeing

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Abstract

Background: The need for dignity and compassion in healthcare is enshrined in policy, but is often difficult to enact in practice and what is precisely meant by these concepts is unclear. In this paper, we have explored theoretical underpinnings which form the basis of a lifeworld-led approach which was used in a research study to support the humanity of service providers and users alike.

Aim: In this article, we share our analysis of what we have learnt after undertaking an innovative appreciative action research project with patients and staff in a stroke ward with the aim of exploring if a novel phenomenologically driven and philosophically derived humanising framework could be applied in health care. Following the research, we wanted to develop a theoretical understanding of the processes occurring during the research in order to provide a framework and language which could be used to support practical lifeworld developments in the future. We analysed the approach through Participatory and Appreciative Action Reflection.

Findings: As researchers, we found that the approach was underpinned by four key existential principles. The first principle was recognising a mutually arising reality rather than a reality 'out there'. The second was recognising a reality which was constantly changing rather than 'fixed'. The third was recognising that we needed to work from within, as part of a human living system rather than trying to control reality from the 'outside'. Finally, we recognised that this reality could only be accessed through human knowing, including embodied knowing rather than intellectual knowing alone. These principles challenged many of the usual ways of thinking and working within research and healthcare contexts.

Conclusion: Understanding the processes and reality in this way gave new perspectives; enhancing our understandings and views of ourselves, what is important and most importantly what is possible in caring systems.

KEYWORDS

compassion, dignity, humanising practice, lifeworld, wellbeing

INTRODUCTION

Researchers and practitioners highlight the need for more dignity and compassion in health care [1,2]. In the UK, policies and reports have been written to respond to dehumanising and degrading care [3-5]. Although written, they are often difficult to translate and enact in practice. While some changes have been reported, such as developing compassionate leadership in NHS England (London region) and person-centred continence care services (South Region) [6] they are not widely used [7]. We would agree with Feo and Kitson [8: 1] who state that 'Whilst care standards and policy initiatives are attempting to address these issues, their impact [on the ground] has been limited'. There is recognition of low staff satisfaction, from those who do not feel they can provide the caring services they would like to, leading to increasing staff shortages [9,10]. The importance of kindness and compassion has been highlighted in the COVID-19 crisis [11,12]. In the healthcare system, staff faced many extra daily challenges affecting their mental health and wellbeing [13]. New ways of working and practical ways to support human connection have been recognised such as: allowing more autonomy and personal control and creating a greater sense of belonging [11]. It is important that these human considerations are not lost. The purpose of this paper is to be able to contribute ideas and practical steps to the sustainability of kindness, compassion and wellbeing in research and clinical practice as a 'new normal' develops.

In response to the need for more dignified and compassionate care, Galvin and Todres [14] have developed a perspective to understanding healthcare practice, where they take into account what it means to be human. They developed philosophically derived understandings using a lifeworld approach privileging direct subjective experience [14]. The humanisation framework offered describes eight different ways of helping people 'feel more human' including addressing their sense of insiderness, agency, uniqueness, togetherness, sense-making, personal journey, sense of place and embodiment [15].

In a recent study [16], we used an appreciative action research approach to investigate whether the humanising framework could be usefully applied in practice. As part of this larger study, following NHS Health Research Authority NRES ethical approval (14/NE/1046) (CP and CEH) worked in a tripartite group with six previous stroke service users and five staff for nine 1½ hour meetings over nine months. The researchers were also participants carrying out the activities alongside the service users and staff and learning was shared. Together we, patients, staff and researchers, explored our own daily experience of either being on the stroke ward or working as stroke researchers, sharing with each other using arts-based approaches. We then explored each of the dimensions of the humanising framework and how these related to our experiences. The staff were then invited to see how they would like to develop their practice. As part of their response, they wanted to nominate themselves as 'Humanising Champions' and notice and support the development of humanising moments on the ward [16]. They recognised that these moments made a great difference to patients' and their own overall experiences of the ward setting. Some staff participants described this experience as transformational: they saw themselves and their worlds in a much more positive light, with increased self-confidence, sense of possibility and wellbeing at work.

The aim of this paper is to illuminate a theoretical understanding of the processes occurring during the participatory research study into applying the humanising framework to practice, gained through reflective analysis. This is in order to provide a framework and language which could be used to support this humanising practice approach and developments in the future.

PARTICIPATORY APPRECIATIVE ACTION REFLECTIVE ANALYSIS

Following the empirical Participatory Action Research (PAR) study [16], we, as researchers, wanted to broaden our understanding, moving from processes to principles, linking theory and practice. Our reflections, which are the basis of this manuscript, were informed by participatory and appreciative action and reflection (PAAR) [17]. This was closely aligned with the methodology of the PAR study, with a focus on reflection and aligned to the values of caring science and humanising practice. We focused on (a) developing appreciative insights – aiming to understand the root causes of success which may have previously been invisible, (b) what we shared and learnt together and (c) understanding human experience in its many forms rather than assuming one perspective on truth. In this way, we aimed to develop knowledge that would build practical wisdom [18] and enhance human endeavours in the world. The PAAR analysis can be seen as a form of spiral learning [19], covering the same ground but deepening understanding over time through reflections on appreciative insights during the PAR study, informal group reflections between researchers and staff, wider reading and linking with philosophical understandings.

During the research itself, patients, staff and researchers reflected on processes in the meetings. Staff and researchers also reflected informally between meetings through conversations and the occasional e-mail. Monthly reflective/planning meetings were held between CP and CEH (italics withheld) where we discussed what had worked well and what we felt was important to do at the next meeting. We also held regular meetings with the wider research team and gained valuable insights about lifeworld approaches.

After the research, staff led presentations to the nursing sisters and the hospital board, and staff and patients contributed to a hospital open afternoon; with staff sharing their reflections on the process and the effect on their own practice. A small number of staff presented at national and international conferences and workshops. These activities led to ongoing informal group discussions between staff and researchers and deepened the research team's understandings. The research team also reflected during the preparation of presentations and the publication [16] and carried out wider reading around lifeworld, embodiment and living systems to support the linkage between theory and practice.

The aim of the reflective analysis was to explore and illuminate a theoretical understanding of the processes occurring during the humanising participatory research study in order to provide a framework and language which could be used to support practical humanising lifeworld developments in the future. Four principles were identified, which the staff also recognised in their developing approach to, and way of being in, their practice and these are described below.

HUMANISING LIFEWORLD-LED PRACTICE PRINCIPLES

These were intimately bound together and one could not exist without the other but each facet is separated out for ease of reading.

- Recognising a mutually arising reality rather than a reality 'out there'.
- Recognising a reality which was constantly changing rather than 'fixed'.
- Recognising that we needed to work from within, as part of a human living system rather than trying to control reality from the 'outside'.
- Understanding that this reality could be accessed through human knowing, involving embodied knowing rather than intellectual knowing alone.

Each of these will be discussed below. In each section, reflections will be described and incorporated alongside key theoretical insights and understandings and then relevance to healthcare practice and research identified.

A MUTUAL ARISING REALITY

When reflecting on our research groups, we found that we aimed to support and honour relationships and the realities created between people. The research was set up with a tripartite design; the researchers joined the stroke patients and staff as participants so that we could all share and learn together. Our focus was to create and hold a shared space where everybody could contribute equally and the researchers joined in all of the activities in the group. We found that this created a different energy within the group; there was a sense of depth, creativity and free flow of ideas as if we were 'tapping into' a generative force between us. All experiences, however mundane, extraordinary, funny, sad or embarrassing, were honoured and accepted in a non-judgemental way so that people felt safe to share. Holding a 'safe space' felt essential to allow access into this shared reality. This was a very powerful experience, allowing a sense of intimacy within a very short space of time. Staff commented on how they felt closer to each other after one session even though they had often worked together for several years.

Reflections around mutuality arose from our understandings from the lifeworld. When taking a lifeworld approach [14,20], there is the assumption that that 'there is no objective world in itself, nor an inner subjective world by itself; only a world created through mutual arising between the two, forming through awareness and ongoing consciousness' [14: 25]. By 'opening' to others, we were able to experience a wider shared horizon rather than one framed by our own insiderness alone. The epistemological basis for such openness can be supported by Gadamer's work [21]. Here, meanings are not only individually experienced, in other words unique, nor are they only shared, in other words only what we hold in common, rather they are always 'in between', a 'fusion of horizons' in which shared meanings carry both uniqueness and commonality. Here, following Gadamer understanding is 'play' between what people have in common (their common humanity) and the individual and unique meanings each person brings.

Usually within health care, people are separated by their labels or 'categories', becoming staff, patient, relative or manager inhabiting differing realities which may or may not be understood or shared. This sense of an objective 'them and us' can create 'othering' and contribute to a sense of separation from others and possible isolation and loneliness. Healthcare staff report stressful working relationships [22], and patients report feeling insignificant and powerless at times [23]. Monbiot [24] highlighted that we have created modern human societies where it is too easy for people to become cut off from human connection. This categorical, objective way of viewing the world is taken for granted by the majority and is very powerful as it has an influence which is 'invisible' and unrecognised. It can create deep problems as connection is an essential human need [25]. By developing healthcare cultures which recognise the importance of creating mutual realities, we can support greater human connection to flourish.

REALITY IS CONSTANTLY CHANGING AND HAS MANY POTENTIALITIES

When reflecting on the research groups, we, as researchers, found that we tried to remain open to possibility and not control the research too much. We set minimal controls: a set start and end time for the groups and a structure of introduction and recapping, creative activity, discussion and closing. Open discussion and creative activity encouraged others to contribute and we were responsive to whatever people brought in that moment.

From month to month, rather than setting sights on predetermined outcomes, we let go of control and allowed things to happen. We felt we had to 'trust the process'. This felt strange as usually, we were in control and had expected (even if sometimes deliberately vague) outcomes in place. We formed current intentions for how we wanted to proceed and curiosity and interest in what may happen. This allowed us to remain aware of the present and possibilities which came from the group, increasing the level of enthusiasm as people felt seen and appreciated.

Hörburg et al. [26: 62] drawing on the work of Merleau-Ponty highlighted that 'we are opened to the world we touch and are touched by at every point of our being and this implicates an existential vulnerability'. Every moment contained possibilities and necessary vulnerabilities. In one group, we as researchers highlighted that we did not know what would happen in the research which surprised the other participants. Following this, the dynamics in the group changed and the energy level increased further. Us 'not knowing' left space for knowing from all of those in the situation to be shared. This contributed to the building of trust between us and trust in a shared state of 'not knowing'.

Using a lifeworld-led approach, we recognised life's seamless holistic quality full of interrelated horizons: every moment or event being part of a wider horizon and the current 'figure' of an expansive interconnected ongoing 'background' of experiences, meanings and understandings [14]. These interrelated horizons create a network or web of numerous possibilities; in each moment, there are many possible ways for the current 'figure' to emerge. In this way, we are creating and recreating our world at every moment by living it. 'Not knowing' [27] allowed kaleidoscopic movement between the shared realities of members of the group experienced through a sense of curiosity, fun, laughter and play.

Several staff members said that they had remembered and got in touch with why they had become a nurse or a therapist and were re-energised by this new experience. The person could be themselves in all of their evolving complexity. In a sense, the whole of the person was welcomed, which we feel is key. Lacey [28] said: 'Reflect for a minute on what it feels like to be welcomed. The word means, simply, "come and be well" in my presence. It's a fundamental human experience, and a very crucial one. When I am welcomed, I feel good. I can be myself. I relax and feel unself-conscious, energised, happy. On the other hand, when I am not welcomed, I doubt myself, turn inward, shrivel up. I feel excluded, not accepted, and not acceptable. This is painful. If it happens often enough, I will question my own self-worth'.

A healthcare culture dominated by a view of reality which is objective and 'fixed' with specific outcomes can have an inadvertent effect on trust and care. Clinicians may base practice on the past (pre-determined) with an eye to the future (outcomes/targets) and lose awareness of the person in front of them in the present. Remaining in their own lifeworld, taking full responsibility for the encounter creates separation. Holding responsibility alone can feel very onerous. Powerlessness may ensure if they do not feel able to do anything about their 'fixed' environment.

Practice would be greatly enhanced if they felt allowed to share responsibility with those they are caring for, exploring the many possibilities in the moment through not knowing and curiosity, and learning together what is needed in that moment to help future recovery and healing. After a recent workshop, a speech and language therapist used this approach. Rather than starting the outpatient appointment as usual, she asked Bob (pseudonym) what he would like to do. He said 'Go for a walk'. Walking together, side by side created a less intense space for speech therapy and gave Bob many different things to practice commenting on. His speech greatly improved over the following weeks during their walks.

We need to be aiming to create shared spaces that energise everyone, researchers, staff and service users, where positive futures can be created together.

PART OF A LIVING SYSTEM

When reflecting on the research groups, we, as researchers, sensed that we were working within something that was larger than each of us alone. We felt that we were tapping into a caring, creative force or energy that was flowing within and between us, created by the conditions of letting go /not knowing and safety. Over time, we gained confidence that when we were able to be part of this safe space, something deep and meaningful would be shared.

Both service users and staff shared stories of caring where small moments made a big difference to their overall healthcare experience. One service user told of how moved she was when a care assistant gave her strawberry yoghurt and said that she had remembered it was her favourite flavour. Another service user told of her distress when at night, she had asked for a cup of tea; to be told the nurse was too busy and later that night hearing the nurse laughing over a cup of tea with a colleague. These small moments

were still vivid for the tellers many months after the event. From an objective viewpoint, these moments could be seen as a fleeting positive or negative event, but when reflecting on our intertwined human experience, these small moments could be seen as times when there was either meaningful sharing and a dip into the larger living system of human connection and care, or distress at being further alienated from it.

In the groups, we sensed that the caring creative energy was subtle, delicate with its own flickering 'aliveness', rather like a flame, held by conditions within the group. It could be diminished or lost in an instance. When staff developed their practice, through recognising and supporting 'humanising moments' between people on the ward [16], we discussed the possibility of translating their practice into guidelines. Staff felt strongly that their new way of being and seeing could not be translated into objective rules or techniques. They felt this would lose the subjective 'aliveness' of the process. It had to be experienced, lived and embodied to be appreciated and understood.

Wheatley [29] writing about this 'aliveness' highlighted that human systems are living networks, based on relationship, creating order through exchanges of information and energy and responsiveness in an ever-changing environment. By taking a lifeworld approach, we were striving to be faithful to the 'living' everyday nature of the service context and how service users and providers experienced it. Here 'what goes on' is always in the context of a seamless flow of experience and attending to the lifeworld provides access to the aliveness of experience [30]. Welwood [31] describes accessing this living system as 'open ground' which we all share, and which can be experienced as a sense of aliveness, joy and wellbeing.

In healthcare, external, objective control of the world, essential for addressing medical bodily needs, is the focus. However, if ignored, valuable knowing from our living human systems, caring and creative energy, sense of possibility and aliveness will be lost, and our human responses will become diminished.

HUMAN KNOWING – EMBODIED NOT JUST INTELLECTUAL KNOWING

As researchers, we wanted to use embodied activities in the groups. At the beginning of each research session, we shared a blob people© diagram [32] each seeing which blob person appeared to share our current mood, bringing us 'into the room'. We invited exploration of our own experiences and sharing understandings through simple arts-based activities. For example, we used a technique we called 'wool and stones'. Participants were invited to create an image of a day as a stroke patient, service provider or stroke researcher handling wool, string, ribbons, rough stones, coloured glass stones or selecting images which resonated with healthcare experiences. Initially unsure, because as adults they rarely used art, people became enthused once they were invited to pick up whatever interested them and their body was allowed to respond. The representations of their experiences which were often very intimate, rich in metaphor and occasionally brought new insights to the creator. People often valued their creation and either wanted a photograph of it or to take it away with them. When planning and running the sessions, we were increasingly being guided by what 'felt right' rather than what we thought was right. We relied on our embodied knowing, and this was a key part of 'trusting the process'.

Merleau-Ponty highlighted that direct experiences are created through and held in the body [33-35]. Our human knowing is always *more than* or *in excess of* what we can put into words or think about [35]. Pallasmaa [36: i] highlighted how our body has been 'undervalued and neglected in its role as the very ground of embodied existence and knowledge as well as the full understanding of the human condition'. As humans, we have much deeper way of knowing than is often recognised. Claxton has highlighted how embodied knowing is metaphorical, complex and networked, and that the specific always carries the whole [37]. Gendlin [34] and Todres [35] highlight the deeper and richer way of knowing formed in our felt sense when we access the whole rather than putting something together from parts, as in conceptual knowing. The artist Anthony Gormley [38: 36] highlighted how deep human understanding comes from tuning into our body said 'the return to the body is not about representation – it is to engage the total sensorium of consciousness' – linking back to the 'open ground' we all share.

Healthcare and research have been dominated by the intellect. In understanding and practice, linear thinking has been used to explore how objectified people, places and systems relate to each other. We explore cause (processes) and effect (outcomes), leading to specific approaches to problem-solving and clinical approaches which rely on rational responses. We make the (misleading) assumption that humans are rational, ignoring meanings from our embodied experiences [14]. We severely narrow down the range of possible knowings which can be drawn upon to guide our caring action and we ignore our personal lifetime of human understanding.

The four principles above highlight that the nature of reality is understood to be very different from 'usual' when taking a lifeworld-led humanising approach. This creates new arguments and a logic for (a) understanding limitations within current healthcare approaches and (b) providing opportunities to develop healthcare practice in a more humane way. Having discussed the principles, we will now move on to concluding thoughts for caring practice.

CONCLUDING THOUGHTS FOR CARING PRACTICE

In this paper, we have presented what we have learnt from carrying out one humanising lifeworld-led project and so our concluding thoughts should be seen in this light. We are reflecting on the specific approach we used in this project; we are not claiming that the ideas shared can be immediately and directly translated into everyday healthcare practice. Further work is needed and is being carried out to explore how this can happen. What we are aiming for is to introduce an innovative logic to help others see new possibilities and share an interest in developing caring practice in this way. We suggest that the lack of ability to translate policy related to compassion, dignity and wellbeing into practice is not due to a lack of interest or ability on the part of health care or research staff but due to the fact that they are working within a culture where understandings from a first person, subjective, perspective are less likely to be valued, accessed or understood.

An evidence-based healthcare approach has formed and informs Western health care [39] leading to national guidelines for practice and services determined by measurable outcomes. It assumes a fixed reality 'out there' which we aim to control through the use of our intellect. Researchers may feel that they need to limit themselves by not including their and others' human knowings. Healthcare staff caught up in this technical culture, where the focus can be seen as *Only-Doing*, can easily end up in a vicious circle of ongoing intellectual activity with negative emotional consequences, and a potentially reduced level of care for service users. Youngson and Blennerhassett [40] highlighted the emotional exhaustion, depersonalisation and cynicism experienced, in what they have called the industrialisation of health care. At an extreme, people can feel disconnected from themselves and others, literally feeling 'lost'.

We would suggest that guidelines and measures, although essential, need to be used within cultures which accept, understand and value subjective experience and 'human knowing'. This can be seen as *Being-Doing*, using the multiple understandings which are based on an interwoven 'song' of knowing, morality and the art of applied action, which we all carry with us [14]. Our felt sense, drawing from our lifeworld knowledge, is interconnected in a web-like metaphorical way, the metaphors acting as doorways to unlimited realities, fully engaging our feelings, meanings, cognition and imagination [37]. When this imagination is focused on concern and care for others, empathic imagination can take place [41,42]. We can sense what a situation is like for another person and can respond in a specific and sensitive way to what the situation needs at that precise moment and they can feel fully met [43]. Our felt sense is a rich unending human resource which can be drawn upon to guide compassionate, dignified care and wellbeing for all concerned.

In Figure 1, the grey centre represents the limited perspective when the 'usual' view of only a fixed separate reality, which is understood rationally with an aim of control, is used. When the wider humanising lifeworld principles of recognising a mutually arising, constantly changing reality, understood through embodied knowing and as part of a living system are used, new possibilities can be seen. These include recognition of the power of relationship, working with potentialities, recognising that small moments can make a large difference, and deep knowings beyond words, which have their own creative power and aliveness.

We found that accessing our human felt sense and embodied sensitivity/ intelligence were not something new that we had to learn, like a new technique. It is something we do naturally because we are humans. It would be helpful to support people to remember and use these resources and ways of knowing while training for research practice and professional practice, as they can be easily lost [44,45].

We have reflected on the key implications for practice which are highlighted below.

Implications of humanising lifeworld-led practice

Explicitly describing humanising experiences and processes, raising awareness of them and valuing their presence, offers opportunities to render them more visible, enhancing and embedding such practices in healthcare and research cultures. We restate these key experiences and processes below.

- Staff experience a connection to themselves and their own human resources, their intellect, imagination, feelings and meanings.
- Staff gain confidence in themselves and their abilities to respond in sensitive and meaningful ways.
- Service user and service provider vulnerabilities and possibilities are accepted. Previously perceived difficulties are not avoided or dismissed. They are faced, accepted and addressed.
- Researcher vulnerabilities and possibilities are recognised and shared, supporting greater sharing from participants.
- Service users and providers, researchers and participants experience a feeling of connection with others, being 'seen' being 'heard'.
- Service users and providers and co-providers; researchers and participants experience a sense of trust between each other.
- Direct care is privileged, whist recognising that records also need to be kept.
- It is not assumed that we can control all events in life. When things do not work out as expected, or mistakes are made; people are not automatically blamed. Those involved and

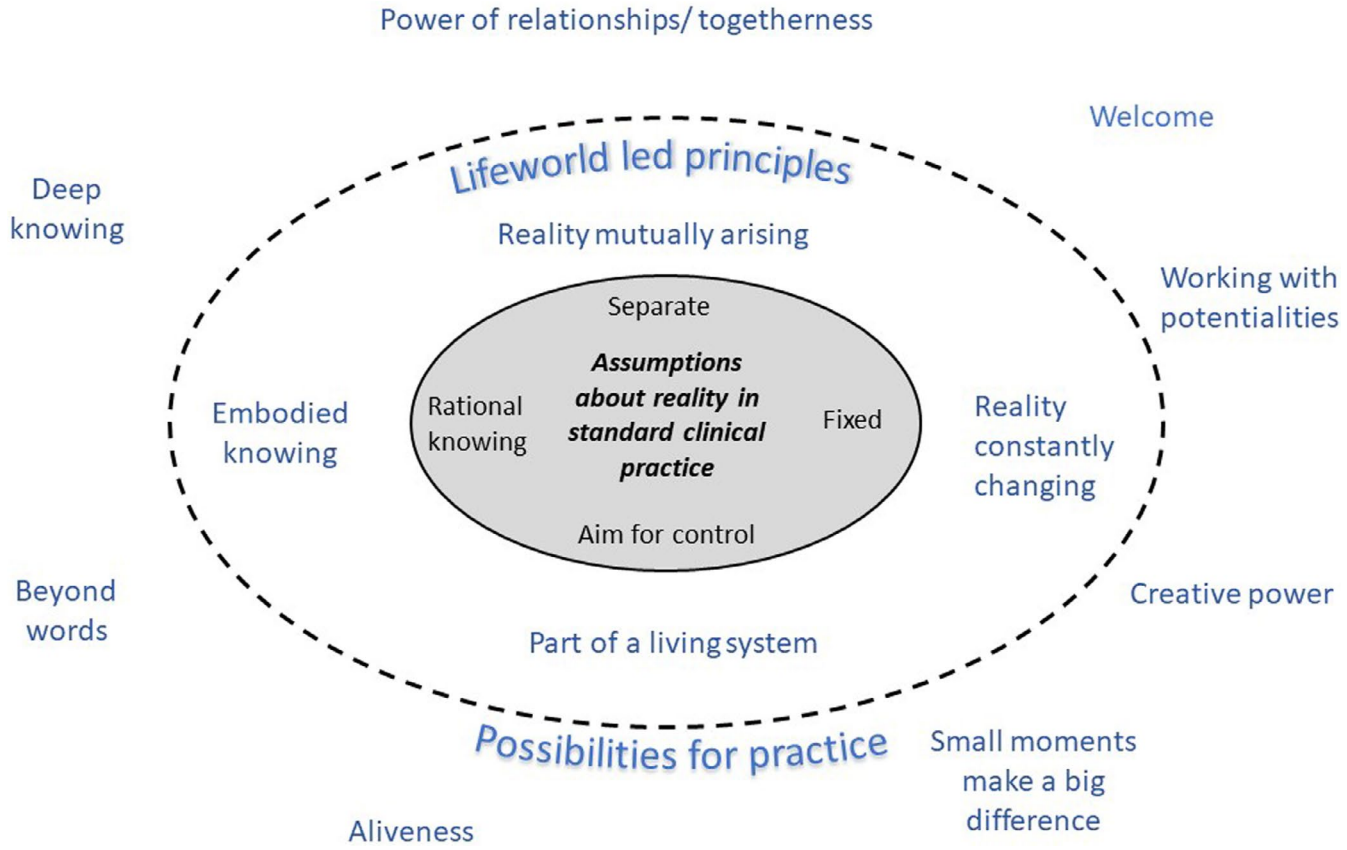

FIGURE 1 Humanising lifeworld-led practice principles

affected are brought together to see what can be learnt to ensure the instance cannot recur and reparations are made.
- This releases a sense of wellbeing and vital energy for all concerned.

We suggest that humanising lifeworld-led practice is simple but not easy. We found that for many staff once they had completed the nine sessions, they had a new 'way of seeing' [14: 4] because they had reconnected with their own embodied as well as intellectual knowing. In one way, it was easy and straightforward – a case of remembering. However, because this way of seeing has its own aliveness and responsiveness it is easy to forget or lose the connections to it when faced with the dominant technical culture day in and day out. We suggest that we need to develop ways to keep the awareness and access to humanising practice alive. Also, the approach is not 'easy' in that the power in this approach relies on drawing on our authentic embodied resources[35,42]. It is not possible to learn humanising practice as an add-on communication technique or just 'talk the talk', as a lack of embodied congruence will be perceived immediately.

By drawing on this approach (Being-doing), those in caring situations would have a connection to all their human resources: embodied knowing, intellect, imagination, feelings and meanings, allowing direct care, caring, dignity and wellbeing to come to the fore. We are hoping to develop a language and understanding to support a humanising lifeworld-led approach as an accepted part of everyday practice, and this paper is an initial step on this journey. Having reflected on our research process and experiences, some key principles with practical usefulness have emerged and it is our hope, building on this foundation that when people start their work day in health care they do not say what am I going to *do* today? But, how am I going to *be* today?

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CONFLICT OF INTEREST

No conflict of interest.

AUTHOR CONTRIBUTIONS

CEH led the main study on the stroke ward, led the reflective analysis and drafted the manuscript. CP facilitated the groups in the main study, participated in the reflective analysis and drafted the manuscript. KG designed the overall main study, participated in the reflective analyses and drafted the manuscript. All authors read and approved the final manuscript.

ETHICAL APPROVAL

The original stroke study received NHS Health Research Authority NRES ethical approval (14/NE/1046).

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