

Facilitating a dedicated focus on the human dimensions of care in practice settings: Development of a new Humanised Care Assessment Tool (HCAT) to sensitise care.

Title Page

**Facilitating a dedicated focus on the human dimensions of care in practice settings:
Development of a new Humanised Care Assessment Tool (HCAT) to guide care.**

Running Head: A dedicated focus on humanly sensitive care

Category: Research that draws on ideas from the humanities (phenomenological philosophy)

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Abstract

There is limited consensus about what constitutes humanly sensitive care, or how it can be sustained in care settings. A new Humanised Care Assessment Tool may point to caring practices that are up to the task of meeting persons as humans within busy healthcare environments. This paper describes qualitative development of a tool that is conceptually sensitive to human dimensions of care informed by a lifeworld philosophical orientation. Items were generated to reflect eight theoretical dimensions that constitute what makes care feel humanly focused. An action research group process in 2014-2015 with researchers, service users, healthcare professionals in two diverse clinical settings (stroke rehabilitation and dermatology) was used. Feedback on conceptual content, transparency of meaning and readability was then gained from a panel in Sweden and third year student nurses in the UK.

The tool can be applied to attune staff to human dimensions of care, offering items which point to concrete examples of humanising and dehumanising features of practice in ways that have not yet been fully captured in the caring literature. Based on theoretically-led experiential items, with dedicated focus on what makes people feel more, or less than human, it may offer improvement on available assessments of care.

Key words: Humanised care; lifeworld approaches; person centred care; assessment of care; questionnaire development; phenomenologically informed qualitative instrument development.

Introduction

There remains lack of consensus of what constitutes caring in a health context. Further, language to describe caring *for* (direct bodily care) and caring *about* (a desire to help) is used interchangeably (Cohen, 2011). Morse, Solberg, Neander, Bottorff & Johnson, (1990) identified five working definitions of the concept of caring; these were caring: as a trait, as an ideal or moral imperative; as an affect; as an interpersonal interaction or as a therapeutic intervention. While concepts of caring are difficult to define they are commonly associated with attitude, ability, attributes, characteristics *and* sets of behaviours (Finfgeld-Connett, 2008; Strachan, 2011). In addition, caring has long been associated with presence, such as giving and making time for persons, with emphasis on interpersonal connection (Ersser, 1997). Knowing and being with persons is therefore also central to care (Swanson, 1990).

Caring has also been delineated as not just a matter of professional knowledge but also a form of 'living' underpinned by certain capacities (Galvin & Todres, 2009). This strikes at the heart of difficulties in developing a way to set out what successfully constitutes meaningful care. What might such care 'look like' in everyday practice? It is difficult to provide an approximation of behaviours resourced by these caring capacities: that is, 'what it takes' to meet patients as human persons in both their vulnerabilities and their possibilities.

The purpose of this paper is to describe how we a) used phenomenologically informed theory to underpin and develop a new humanised care assessment tool and, b) identified

item content and assessed potential face validity. The tool is novel in that it uses theoretically-led *experiential* items informed by phenomenological ideas. Because the tool offers a dedicated focus on what makes people feel more or less than human, it may contribute to improvements on available assessments of care that have been inconclusively debated.

Background

Various attempts to *measure* caring have been explored at length. Watson (2009) evaluates several instruments designed to measure caring and comments on the complexity of this task: "Measuring Caring? Yes, this is work that offers multiple means to measure caring while still acknowledging that any measure is only a manifestation, an indicator of something deeper... These instruments serve as pointers" (Watson, 2009, p.8). Further, within the literature, definitions of care generally fall into two 'camps': a) affective 'caring about', focused on the attitude, attributes and demeanour of the person administering caring, and b) instrumental caring for, focused on tasks or what is done while caring for someone. This dichotomy in perceptions of caring has been apparent since the earliest empirical research into caring (Larson, 1984; Lea & Watson, 1996). There is also a demonstrable gap between what nurses think patients want of care, and what patients expect. There is evidence that nurses value psychosocial aspects of caring above instrumental aspects, and patients prefer nurses to be caring in the instrumental sense (Larson, 1987). This effect has also been observed in more recent empirical work about perceptions of caring (Watson *et al.*, 2003).

All this complexity is against a backdrop of what we know are failings in care. An extensive literature points to how patients do not feel met as human beings, with examples of how certain kinds of everyday care situations can even add to suffering (Berglund, Westin, Svanstrom & Johansson Sundler, 2012; Fridth *et al.*, 2015). This includes particular *kinds of injustices* (Carel & Kidd, 2014) where patients may experience a kind of deeply harmful devaluing that is in apparent in every day healthcare situations. In response to this unacceptable problematic state of affairs, a European caring sciences development, coined 'lifeworld led care' has been evolving (Todres, Galvin & Dahlberg, 2007). The aim of this development is to provide directions for caring practices that are able to support care that is person centred but up to the task of meeting humans in a way that is deeper than 'patient-led care' (Dahlberg, Todres & Galvin, 2009). If care is to be meaningfully person centred, for the purposes of this present paper, this refers to care led by a view of the person as humanly living in the seamlessness of existence given by the lifeworld. Inherent in this particular view of the person are temporality, spatiality, embodiment, sociality (or being in relation to others), as intertwined experiential phenomena within the lifeworld.

There is no shortage of studies that use a lifeworld perspective which indicate problems. In a wide range of settings patients describe experiences *as less than human* (for example, Almerud, Alapack, Fridlund, & Ekebergh, 2007; Elmqvist, Fridlund & Ekeberg, 2012;

Johansson & Ekebergh, 2005; Karlsson, Ekeberg, Larsson- Mauleon, & Almerud Österberg, 2012). Further, key philosophical writings illuminate some foundational problems of being human within healthcare situations. For instance, in her seminal text, exploring the meaning of illness, Toombs (1993) evocatively describes the different perspectives of both patient and physician. She underlines the need for a lifeworld perspective in practice to reconcile these first person and third person views.

All this constitutes a complicated situation that requires close attention if attempts to understand what it takes to feel more human, or conversely, what kinds of assailments create feelings of being less than human, are to be meaningful. At the same time, for the most part, care is delivered within a system that is sometimes necessarily, by its nature, reductionist in orientation. Healthcare is shaped by medical specialties focused on fixing physical deficits and/or seeking somatic causes. Further, it is well known that physical diseases affect more than the body. For instance, thinking about the present study research settings, dermatology and stroke care, specific examples are apparent. Wahl, Gjengedal, and Hanestad (2002) illustrated the bodily suffering of a long- term skin condition that permeated every aspect of the patients' lives. A further example is offered by Luker, Lynch, Bernhardsson, Bennett, and Bernhardt (2015) who have revealed patients' needs at an existential level that require an orientation beyond stroke 'rehabilitation, rather than being focused on only maximising bodily function. This is familiar and generalized healthcare response to illness: A split between mind and body in care, where there may be problematic emphasis on the body as only a biological 'thing'. At other times such emphasis may be acceptable to some patients, perhaps in some simple treatments or day case procedures.

Given all these intricacies, (which include the meaning of being ill, being on the receiving end of treatment, discontinuities between the experiential seamless flow of the lifeworld and the challenges of a sometimes necessarily technical-rational healthcare world), it is not difficult to see how dimensions of feeling human can be easily obscured or disappear altogether. What constitutes a sense of feeling human is highly complex and appears to be closely related to a sense of human dignity.

Therefore, we argue, to enhance humanly sensitive practice, health professionals should focus upon how they can work with patients to feel human rather than just a physical body. To do this, professionals need a beginning place, which has its foundation in lifeworld theory. Here caring practice is attentive to restoring patients to their possibilities and connections within their lifeworld, even in limited ways. This can be achieved by attending to 'what it is like' for the person. For the purposes of this present paper, by specifically attending to eight dimensions of care that respond to a sense of being human as *humanising directions* for practice, (dimensions referred to as the 'Humanised Care theoretical framework' Table 1), (Galvin, *et al.*, 2016; Todres, Galvin & Holloway, 2009).

Table 1: Humanising questionnaire items grouped by humanising dimension

<p>Sense making---loss of meaning Update patients on treatments regularly Understand the everyday consequences of treatments or care plans, which have to be carried out by the patients themselves Keep patients informed at regular intervals when they are awaiting results Assure patients that they can always call for advice Acknowledge, with each patient, the fear that can come with health conditions Use non clinical language when talking with patients Help patients feel comfortable enough to ask questions Build trusting relationships with patients and their significant others. Repeat information about what is happening to patients regularly Offer sensitive explanations on what is happening (now and in the future Create a sense of calmness (when possible)</p>	<p>Embodiment--- Reductionist view of the body Be aware of the personal meaning any bodily (physical) changes for the patient Consider the emotional aspects of the patient's treatment or condition Check that patients are comfortable Think of the patient as a person and more than just a body Discuss each patient as a person (not just health condition or case) when sharing information with other health professionals Have the time to reflect on my own feelings Be aware of the physical impact of bad news for the patient Be aware of the physical impact on me, of giving bad news Notice what makes the patient feel tired Notice what makes the patient feel relaxed Notice what makes the patient feel energised Help patients understand the changes that may be happening to them</p>
<p>Insiderness---Objectification Try to see the person behind the illness or condition Show that you want to know 'what it's like' from the patient's perspective Provide care that is not only technical/task focused Be aware of the anxiety patients can experience when waiting for results Show that you want to know about patients fear about their situations Notice what affects your patient's mood Give patients time to talk about their emotional response to their illness/condition Frequently ask patients how they are</p>	<p>Uniqueness---Homogenisation Consider how generic treatment pathways fit with the individual patient Remember small details about patient's personal stories Consider the different responses patients can have to the same illness or condition Ask the patient how they assess their own health Seek out how care could be adapted to suit the individual patient's situation Remember small details about patient's personal care preferences Use patients preferred name</p>

<p>Personal Journey---loss of personal Journey Focus on what is of concern to the patient (even if outside or unrelated to treatment) Ask patients how they are finding their journey through care Find ways to help patients stay in touch with important things from their everyday life Help patients to stay close to their own everyday routines Ask patients how it is going for them Take space to listen to the patients worries, even if they cannot be resolved Offer support to patients moving through a system they are unfamiliar with Appreciate that how a patient sees the severity of their illness or condition may differ from my own Regularly check that treatment is going okay from the patient’s point of view Recognise the importance of a regular review of care with the patient</p> <p>Make sure patients are treated by a named or consistent member of staff. Be prepared to change direction if treatment is not working for the patient Consider how patient’s future aspirations may be affected by their current treatment.</p>	<p>Sense of place---Dislocation Create a welcoming environment Consider how the care setting we operate in can be initially unfamiliar to patients Where possible, to help patients to have some meaningful possessions close at hand Focus on making the patient feel at home Where safety concerns allow, adapt the environment to make it as homely/personal as possible Notice barriers that can get in the way of patients feeling welcome Notice barriers that can get in the way of families feeling welcome Consider how the surroundings (e.g. noise, images, smells, friendliness) makes patients feel comfortable Consider how the surroundings (e.g. noise, images, smells, friendliness) makes families or significant others feel comfortable Consider how the surroundings (e.g. noise, images, smells, friendliness) makes staff feel comfortable Consider how the environment (e.g. noise, images, smells, friendliness) could make patients uncomfortable Consider how the environment (e.g. noise, images, smells, friendliness) could make patient’s significant others feel uncomfortable Show patients where they can find peaceful spaces Encourage other staff to introduce themselves by name and role Provide information about how the service works (meal times etc.)</p>
<p>Togetherness---Isolation Take steps to put patients at ease Be able to support colleagues As far as possible facilitate contact with important people in the patient’s life Consider the patient feelings about being isolated Show patients you are pleased to see them when they arrive for treatment Encourage patients to support each other, wherever possible and when wanted Make sure patients know your name and role Notice patients at particular risk of isolation Introduce patients to others who share their condition, when wanted Provide patients with information on peer support Ensure families and friends feel welcome Feel supported by colleagues Have a sense of a human connection with the patient Care about the wellbeing of my colleagues</p>	<p>Agency---Passivity Ask patients about their expectations of care and treatment Notice how staff behaviours could create embarrassment, shame or vulnerability, during treatment Give patients the skills to manage their own conditions Ensure that the patient has a means of communication with a named health service provider on discharge Support patients to have a say in their care or treatment Take an interest in what patients tell me about how they like things done Seek out flexibility in the system to respond to patients priorities Explain to patients where there is no flexibility in the system and why Give patients the confidence to manage their own conditions Try to find out information that the patient wants on their behalf Try to involve significant others as the patient wants Where possible offer patients choices about what happens to them next</p>

The items summarised in Table 1 are intended to reflect the eight dimensions. For example ‘offer support to patients moving through a system they are unfamiliar with’ is linked with the dimension Personal Journey/ Loss of personal journey; ‘try to see the person behind the

illness or condition' is linked with the dimension Insiderness/Objectification; and 'be aware of the patients unfamiliarity with the environment' is linked with the dimension Dislocation/Sense of place).

The historical development of this conceptual framework for humanised care has come from a phenomenologically oriented reflection on what it is to feel met as human as a value base (Todres, *et al.*, 2009). However, we believe it is legitimate to take a further, although cautious next step. This next step is to provide a series of 'experience-near' items (these are characterised as experiential, concrete examples from the everyday) that can be recognised by both professionals and patients as indications of what it takes to provide humanly sensitive care within a care delivery environment. The items, if theoretically coherent as 'a collective' may concretely point to directions within healthcare settings to respond to patients in highly humanly sensitive ways. While a lifeworld approach can provide directions for care practices *directly* from qualitative research findings, the technical-rational context of healthcare also places increasing demands on research to find ways of assessing impact. This means providing evidence that strategies to improve or enhance practice have made a difference. This requirement calls into view the need for methods and kinds of assessments that can be investigated in a range of healthcare environments, firstly, in order to show that phenomenological oriented research does indeed make a difference, and secondly, that insights about human experience are essential if care is to be *care*.

Further, an assessment based on theoretically-led experiential items that are 'concrete' may offer improvement on available abstract measures of care that have been inconclusively debated: The Humanised Care Assessment Tool (HCAT) may point to what constitutes care up to the task of meeting persons as humans within any human service environment. Therefore, our work to develop a humanised care assessment tool, although contentious and methodologically 'difficult', we suggest adds to the range of supports needed to keep a focus on what really matters to people, and is potentially attentive to more existential issues that are easily overlooked. We therefore hold onto our philosophical underpinnings but recognise that we are trying to do something that is challenging: in balancing being faithful to the phenomenological foundation of 'what it is to be human' while and at the same time engaging in the process of questionnaire development. At the pivot of such a balance is this question: what is the HCAT for? We offer HCAT as a sensitising tool. If used to bring into view aspects of care that are humanising and dehumanising in a variety of care environments, this can open up practice development strategies that are meaningful to both patients and staff, and which may have potential to go beyond top down policies and strategy. It may offer one way to reconnect staff with dimensions of care that they value, and which can easily become obscured.

The development of HCAT is built upon humanised care values offered by Todres, *et al.* (2009), articulated further by Galvin and Todres (2013). Currently there is no standardised way to make value judgements about consistency of the human aspects of care as

delineated by the Humanised Care theoretical framework. Such an instrument might be usefully applied in self-assessment of care settings and in further research assessing the impact of applications of humanising care theory that are now underway (Borbasi, Galvin, Adams, Todres, & Farrelly, 2013; Galvin *et al.*, 2016; Hemingway, 2012).

The Study

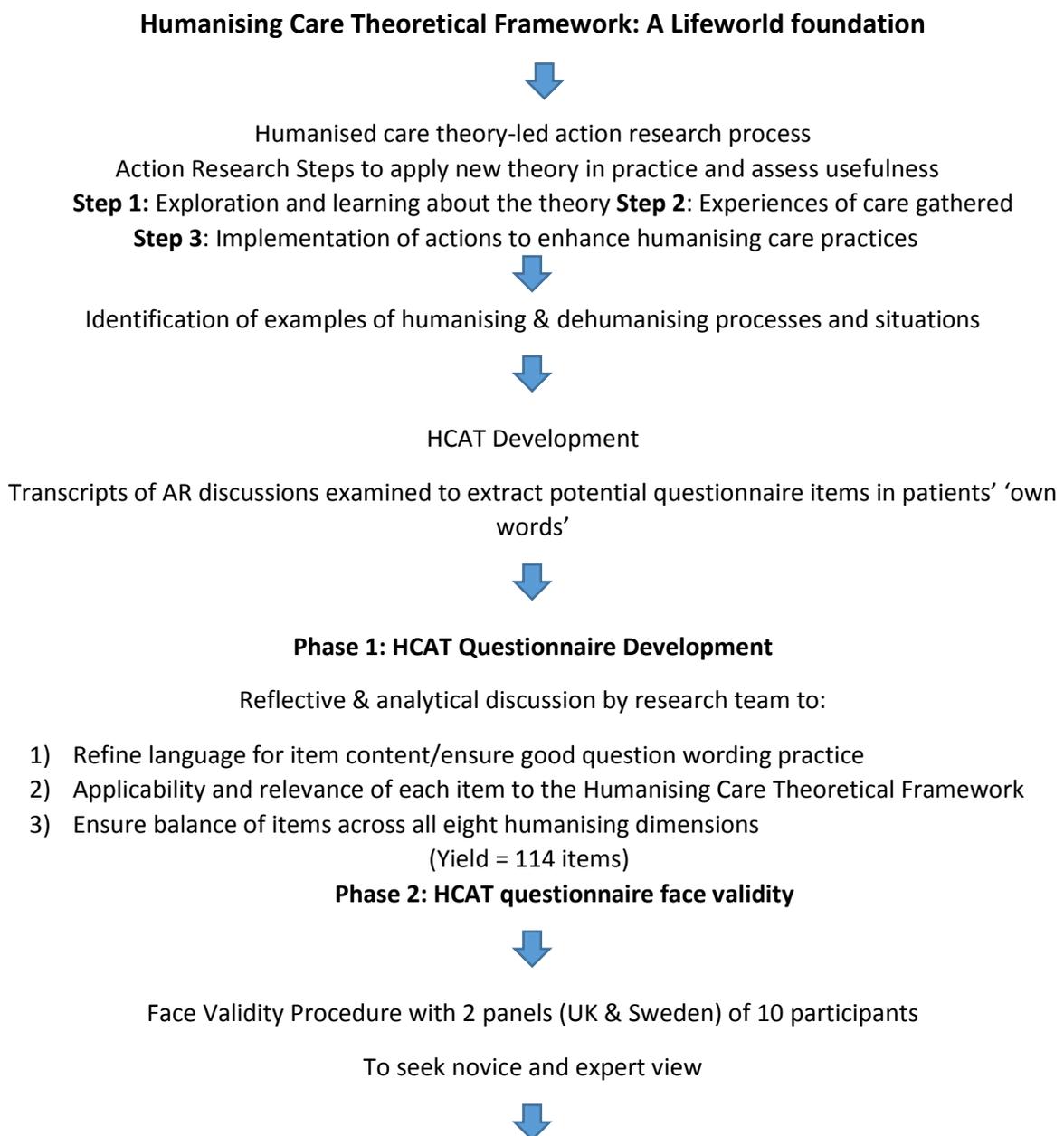
This present study is part of a larger overarching project (Galvin *et al.*, 2016) that uses a lifeworld perspective within a participatory approach with the aim of developing insights for practice that can lead humanly sensitive care in transferable and widely applicable ways. As a characteristic of merging two approaches we wish to point towards impactful practice outcomes and offer ways of both achieving and assessing care improvements beyond the overarching project. The HCAT development is one outcome of this wider project concerned with investigating practical application of a conceptual framework for humanised care through a theory-led action research design. Eight theory-led action research sessions (ARS) were conducted in two locations (a dermatology outpatients service and a stroke rehabilitation unit) 2014 -2015. The group's aim was to explore transferable benefits of a new participatory theory-led strategy for improving the human dimensions of human services. In ARS Step 1 both action research groups, facilitated by academic partners, learned about new humanisation theory and explored eight humanising dimensions that form the Humanised Care theoretical framework (see Table 1), relating them to their own experiences of humanisation and dehumanisation in each setting. During ARS Step 2, groups carried out humanised care assessments of their setting, drawing on each member's experience of care in the setting, collecting examples of humanising and dehumanising practices and then deciding how to take a humanising approach forward. ARS Step 3 concerned implementation of actions that could enhance practices that attend to human dimensions of care and development of transferable strategies for other care settings beyond the project. A key transferable outcome of this overarching three step action research process comprised development of the humanised care assessment tool, designed for use by healthcare professionals with a focus on characteristics of care settings in humanising terms. The focus of this present paper concerns how we used a phenomenologically informed theoretical underpinning to develop item content and assessed potential face validity. Based on experiential items, with dedicated focus on what makes people feel more or less than human, this may offer improvement on available assessments of care that have been inconclusively debated. It may offer one way to make value judgements about consistency of human aspects of care.

Aim

To develop a standardised approximation of everyday practices that provide focus on assessing human aspects of care.

Methodology

The steps in the research process began with a novel participatory research strategy combined with a lifeworld theoretical approach. The action research process was then followed by a two-phase sequence of activity to firstly, develop the questionnaire format and item content, and secondly, assess face validity and refine the assessment tool, see Figure 1. One advantage of theory-led action research processes was to develop descriptive examples of humanised and dehumanised care, which were subsequently used to inform HCAT content development.



Examined all items that were identified and rated 'not clear' or 'not relevant' by 3 or more respondents



HCAT Questionnaire refined [see Table 2]

Items = 109

Ethical Considerations

Ethical and research governance approval was secured from University Research Committee, the Proportionate Review Sub-Committee NRES Committee North East-Sunderland, UK (REC Reference 14/NE/1046 IRAS project ID 150261) in addition to local research governance procedures within each of the NHS settings. Prior to written consent participants were given an information sheet and opportunity to ask questions. All participants were informed of their right to withdraw at any time. Data were stored and used in accordance with the NHS code of confidentiality, the Data Protection Act and the University data management policy

Questionnaire Development

Phase 1

Item generation: Numerous items describing behaviours exemplifying all 8 dimensions of humanising care framework were needed to provide adequate content cover to undergird face validity of the questionnaire. We aimed to cover each of eight dimensions with several items, attempting to enhance the questionnaire's sensitivity to changes in the care environment that may be observable and potentially measurable. As action research groups engaged in extensive discussion of experiences of humanised care, the transcripts from these discussions provided the starting point for examples of humanised practice to derive items. The process of item generation involved members of our multidisciplinary research team reading transcripts to identify examples of humanised and dehumanised care with the Humanised Care theoretical framework as a helpful guiding context. These examples were then collated, refined and subsequently discussed at length by the authors. The purpose of these discussions was firstly to discuss the relevance and applicability of each item to each of the eight theoretical dimensions and secondly, further refine phrasing (e.g. avoiding double barrelled items (Johns, 2010)).

Additional items were also generated, through a reflective group process that considered the humanised and dehumanised item content and balance across all eight dimensions to yield a total number of 114 items. These items summarised in Table 1 are intended to describe: Sense making/loss of meaning (e.g. 'update patients on treatments regularly'), Personal Journey/ Loss of personal journey (e.g. 'offer support to patients moving through a system they are unfamiliar with'), Homogenisation/Uniqueness (e.g. 'use patients preferred name'), Togetherness/Isolation (e.g. 'make sure patients know who you are'), Insiderness/objectification (e.g. 'try to see the person behind the illness or condition'), Embodiment/ Reductionist view of the body (e.g. 'avoid using clinical language where

possible'), Dislocation/sense of place (e.g. 'be aware of the patients unfamiliarity with the environment'), Agency/ passivity (e.g. 'give patients the skills to manage their own conditions'),). Half of the items emerged from the transcripts directly and half were written by the research team to reflect eight humanised care dimensions in a balanced way. In addition, we wanted to create dummy items to observe if these items would be differentiated from the humanising care items, and check that there was variability in responses. Example dummy items included 'Be organised when booking annual leave' and 'actively seek promotion', (n = 13 items). Please see Table 1 for all questionnaire items grouped by humanising dimension.

The HCAT questionnaire format

All 114 questionnaire items were arranged on a five-point ordinal response scale, asking respondents how often on an average day their work environments enabled various humanising behaviours. Scale responses were labelled 1: Always, 2: Most of the time, 3: Some of the time, 4: Rarely and 5: Never. In addition, items were randomised in the way they were ordered using a random number generator (Randon.org, 2015) to minimise response bias (Schell & Oswald, 2013) (recognising that this made it more difficult cognitively for respondents).

It was important to ensure that the questionnaire remained balanced, that it covered all eight dimensions, but also pointed to dimensions as overlapping but distinct in emphasis. This is the challenge to be faithful to the spirit of a phenomenological foundation with its attention on 'wholes', avoidance of partial views and fragmentation (Spiegelberg, 1984). The eight dimensions are not entities or 'things in themselves', rather they are points of emphases as continuum, they are all equally important but some may be emphasised more or less in various situations. This is one of the greatest tensions in developing an assessment tool that is grounded in a philosophical foundation. Our philosophical foundation requires that we avoid dualistic splits of 'either' / 'or', instead placing emphasis on 'both' because one of the central tenets of phenomenology is that of 'figure' and 'ground'. For instance, in illness, the everyday human world is not 'another side' of illness (as in a coin), rather illness experience is intertwined within the everyday, as figure and ground. The everyday lifeworld is as background: It is the task of humanly sensitive care to restore the possible connections of time, space, others, body and mood and to find wellbeing within illness (Galvin & Todres, 2013). Therefore, we seek ways in this present study to reconcile holding onto such complexity as far as possible, along with the necessary refinements that a questionnaire format demands; a balance of all eight humanising dimensions along a continuum.

The stem question for each item concerns the care environment: If a work culture attends to humanising behaviours, it can be extrapolated that the work environment can facilitate and promote humanly sensitive care. We developed items that characterised 'humanised care', informed by eight dimensions to form a rating scale for a set of behaviours, which we

argue are underpinned by humanising values. It is important to articulate the underlying 'construct' the items are designed to measure (DeVellis, 2012), and in this case, this refers to the values underpinning humanly sensitive care, manifest as eight humanising dimensions of care. Further, the rationale for a focus on the professional's experience concerns the importance of responding to the patients experience as a crucial touchstone for humanised care.

However, there are social desirability issues in asking healthcare professionals to rate their own attention to 'humanising behaviours'. It is difficult to see how respondents would rate their own caring behaviours negatively and at the same time we are aware of complexities of caring work and institutional cultures that can impact practice negatively. Further, we considered that as the 'UK Francis Report' (2013) highlighted the importance of working culture where care takes place, focusing our questionnaire on the context of care in the environment rather than an individual's own perhaps assumed 'volitional' behaviour would be a helpful methodological development. Therefore the stem question is: 'my work environment enables me to'. Also, we considered that this question less abstract than some of our other initial stem questions, it was an 'experience near' question.

Phase 2

Face validity assessment and feedback

Due to the novel nature of attempting to offer a form of standardisation within the context of lifeworld ideas, rigorous face validity investigation, with detailed feedback is necessary. The sample used to assess face validity comprised a group of Caring Science academics in Sweden (n=10) and a group of final year student nurses in the UK (n=10), which formed two panels to obtain feedback from both novice and experienced groups. The time commitment was one hour for each panel member. We were specifically interested in students as a) they are often at close hand to the depths and details of the patients' world, b) are not as culturally embedded in health service milieu as permanent staff and c) may offer improvements in item language that are not already framed within 'professional speak'. We also thought 3rd year nursing students, while novice, would have suitable experience, gained over a minimum of 10 placements and 350 practice hours, to answer items about how their current work place enables caring behaviour focused on human aspects. With regard to the experienced group, it was considered vitally important to obtain feedback from a group who were expert in philosophical lifeworld ideas to a) establish if the questionnaire was perceived to be of value, and b) to ascertain if the assessment could be faithful to human dimensions of care informed by lifeworld theory. Sweden has a long and established caring science philosophy in educational programmes that makes use of these intricate ideas.

Caring Science Academic feedback: Feedback from this specialist panel, was to establish how relevant they thought the items were to the concept of humanly sensitive care, if the items were faithful to a lifeworld foundation. However, this also has the advantage of assessing the questionnaire's face validity in a European context outside the UK.

Additionally, the purpose of this stage of the development was to investigate face validity, in other words, the readability and unambiguity of the items in the questionnaire.

Based on face validity testing procedures described by Broader, McGrath and Cisneros, (2007), we sought general feedback about content, how relevant responders thought the questionnaire items were, and items value as experientially resonant with lifeworld ideas. To address this, the questionnaire was initially piloted with a group of 10 Swedish Caring Science academics, experienced and knowledgeable in the ideas of lifeworld-led care and phenomenological perspectives in caring. We asked respondents to indicate how clear they thought that each item communicated i.e. readability, and how relevant they thought the item was to the concept of humanised care. The Swedish Caring Science academics completed the questionnaire as part of a group. Ten academics were present and each took around 30- 45 minutes to provide feedback on the questionnaire. To note, although English was the second language of the Swedish academics, they all spoke fluent English. Following feedback minor phrasing changes were discussed. For instance, several respondents had noted how the item 'Adjust your pace to get alongside that of your patient', was not clear, so was changed to 'adjust your professional pace to get alongside your patient', to make more explicit the meaning and to facilitate an implicit reference to the care work environment. In addition, for the item, 'show patients where they can find quiet spaces', this was changed to 'peaceful spaces', as the Swedish academics had pointed out that quiet can have positive or negative connotations.

Student nurse feedback: Ten 3rd Year students (8 female, 2 male) from the University of Hull BSc Nursing programme were recruited. Student nurses were recruited during lecture time following a short presentation about the study at which all 3rd year students were present. Nineteen nursing students offered their contact details to participate, and subsequently following invitations, 10 interviews were arranged on 'first-come-first-served basis'. We considered 10 interviews, would provide enough initial information (Guest, Bunce & Johnson, 2006) to establish if any recurrent themes arose regarding clarity and relevance of any of the items. Streiner and Norman (2008) imply that only a small sample is required for this stage of development before administering the questionnaire to a larger sample for further testing.

Each student was invited to attend a 1-hour interview, where they would complete the questionnaire alone in the first half of the interview. Participants were asked to reflect on their current placement and to consider the items in the light of their experience in that care environment. Then, participants were invited to discuss their answers with the researcher, and elaborate on reasons they may have rated items 'not clear' or 'not relevant'. Also, the researcher asked for general feedback on the questionnaire content and explored social desirability issues immediately after the questionnaire was completed. These comments were recorded and used to assist with the face validity analysis.

Refinement of HCAT

Following data collection procedures, feedback from both Swedish academics and English nursing students was collated. Items were initially selected for further scrutiny by the team if they were rated 'not clear' or 'not relevant' three times or more by the participants. These items were then selected for detailed discussion between three researchers with: specialist knowledge on questionnaire development (RW), specialist knowledge about the humanising dimensions of the theoretical framework (KG), and extensive involvement through all stages of questionnaire development, including the face validity testing interviews (CS). It is important to note that not only was the 'clear' 'not clear' ratings considered, but the additional comments as to why an item might not be clear or relevant was particularly useful at this stage.

Some items were considered too abstract, e.g. 'adjust your pace to get alongside that of your patient', and consequently these items were dropped. Others needed simple wording changes to improve plain English and enhance clarity of meaning. For instance, the item 'my work environment enables me to notice my own feelings' was modified to 'My work environment enables me to 'have the time to reflect on my own feelings'.

Whom items were directed towards, also needed careful thought. For instance, an item relevant to sense-of-place: 'notice barriers to being made to feel welcome', respondents asked whom they should be reflecting on, patients or families. As we understood that some care environments may be more patient than family oriented, or vice-versa, we created two items: ('notice barriers that can get in the way of patients feeling welcome' and 'notice barriers that can get in the way of families or visitors feeling welcome'). Furthermore, we considered the item 'Care about the wellbeing of my colleagues' relevant to humanising care environments, despite three respondents' views that this was not relevant.

The exploration of face validity process also involved reflection on the general feedback we received which was overall very positive. For example, we received comments such as: 'I think the questionnaire is useful and highlights areas where staff already do that, and other areas where it makes you think you could improve on that'. Other comments included 'most items address essential aspects of nursing' also, 'I enjoyed completing the questionnaire - at first I thought over 100 items is a lot, but I think it's very detailed and covers everything to do with care'.

In addition, to address our social desirability concerns, student participants were asked if they thought they would be able to answer the items honestly in a work environment. All students said they would feel comfortable to do this, if anonymity was protected. Therefore, anonymity and confidentiality must be guaranteed for those completing the questionnaire to enhance validity.

In summary, following face validity assessment, 10 items were dropped from the questionnaire, five new items were created, and phrasing changes were carried out on 23 items, to yield a final number of 109 items. The balance of items reflecting the eight humanising dimensions are shown in Table 1. The final questionnaire is shown (Table 2/URL see HCAT questionnaire) which reflects current stage of development of the HCAT questionnaire.

Discussion

HCAT points to a collection of behaviours, theoretically underpinned, which attend to broader issues about peoples' existence and not just care focused on body-object. This process facilitates questioning of customary and taken for granted nursing practice. Such an approach is allied to other attempts to revisit values for leading care (Fulford, Dickenson & Murray, 2002, at The Collaborating Centre for Values Based Practice). As a values based approach it can contribute to integration of both meaning and measurement in evidence based practice because:

- HCAT offers one way to keep a dedicated focus on human meaning and everyday experience.
- Distinctively, HCAT provides alternative theoretically informed vocabulary that is up to the task of dedicated focus on both the patient's situation (the existential concern) intertwined with a coherent collection of actions (the instrumental concern) to guide practice behaviours.
- HCAT offers a lifeworld-led translational strategy connecting concrete experiences to an epistemologically robust vocabulary. This can empower reflection which can surface valuable experiential references, thereby reconnecting staff to intuitively informed actions that they may have forgotten. Such experiential reference is more powerful than abstract theory, it can inform the right 'fit' in varied practice situations.

Reflections on why certain acts in practice may be justified or not requires a) invitations for patients to share the way that they experience 'themselves' and b) for professionals to imagine how treatments may affect patients' sense of bodily identity and self, (Slatman, Zeiler & Devisch, 2016) that is, how they are 'in themselves' as human persons. In this context HCAT could usefully guide diverse projects that concern improvements in care and/or reflective work with staff to explore motivations for, and personal resources, that sustain a capacity to care. Here, HCAT can be used as a sensitising values framework, with key touchstones for individual practice. For example, by experienced staff to support novice staff in keeping a firm eye on human dimensions of care as they navigate necessary specialised and technical focus in caring. In a personal development context, for example, a newly qualified nurse could use HCAT as a resource to add to their background understandings of what matters to people. For experienced staff, this sensitisation complements specialism, technical and research evidence knowledge resources, helping them to keep in touch with the less tangible, attuned to the lifeworld background that is foundational in care.

Therefore, HCAT by providing a new vocabulary coupled with practical directions for everyday care because the items *concretely point to directions* to interact with patients in humanly sensitive ways. Touchstones to a lifeworld perspective offered in a distilled form such as HCAT may usefully contribute to policy and helping organisations, for example, supporting more experienced staff to reconnect with their values. Where necessary helping shift the philosophical mind-set of teams working in busy clinical environments where the services are, for example, primarily business or efficiency driven.

Finally, any attempt to measure aspects of caring environments, built on a lifeworld foundation, may offer new directions that are by their nature sensitive to what really matters to people. In contrast to perspectives that are solely professionally or economically driven. HCAT can therefore complement evidence based practice. Firstly, it can be usefully applied to mediate the dehumanising impacts of a necessary economic, statistical and outcome measurement emphasis that is the cornerstone of any drive for efficient and effective healthcare. Secondly it can offer staff an attunement towards what matters to patients that can in turn be integrated with instrumental directions for care that are driven by latest technical evidence. Thereby keeping the human face of ever increasing specialised practice at the forefront. For example, HCAT could be used within an action research framework, to provide setting specific practice development that takes account of patient perspectives within systematic change management projects. It could also inform research about the complex nature and antecedents to patient complaints, offering new resolutions. The HCAT offers a new range of 'experience near' items pointing to concrete examples of humanising and dehumanising features of practice in ways that have not been captured in the caring literature so far. It is grounded philosophically but practically useful to nurses who may have no prior knowledge of lifeworld theory.

All these potential applications offer a step further in directly guiding a dedicated focus for humanised care practices, moving phenomenology into practice impact. There remains a need to move qualitative research onto the next step of resourcing a theoretically coherent knowledge base that can transcend reductionist specialisms, and specifically, uses phenomenologically oriented research towards impactful directions that can make a difference to patients.

Limitations

The HCAT has been assessed for face validity in only two countries and with relatively small panels limited to student nurses and experts in caring science. The cultural sensitivity of the assessment tool needs further exploration with relevant modification to item content. Additionally, adult care student nurses in only one University have been included and further work to replicate procedures in several education and placement providers, and include students from a range of specialities such as mental health and child health, could include allied health professionals and exploration of relevance in diverse settings. There may be potential to test performance of specific items, assess validity and reliability, with

examination of psychometric properties in detail. Exploration of methodological value through a range of international comparative studies is possible. Comparisons of HCAT performance with existing care measurement instruments, and those designed to assess dignity in care, within a range of international applications offer new research directions.

Conclusion

Early indications suggest that the HCAT is understandable and we believe it may be a very promising instrument of value to nurses and a range of health professionals. It offers potential to assess aspects of humanised care within care environments, but importantly, builds on theoretical dimensions that are sensitive to the continuities of the lifeworld that include patient experiences of time, space, being with others, identity and 'living as *this* body'. We wish to offer this new assessment for use as a distinctive values framework, which takes account of what it feels like to be human, as such it can be a valuable resource in helping professionals to reflect on aspects of care that are both humanising and dehumanising.

In conclusion, there are at least three ways in which HCAT can advance activities that attend to foundational features of care that are at risk of becoming obscured or which may be lost altogether in the necessity of efficient and effective services:

Firstly, HCAT can offer a sensitising tool to help professionals stay in touch with the human dimensions of care and to develop practices and initiatives that support this focus, complementing evidence based practice with a sustained human focus that can guide meaningful person-centred care. As it stands the assessment tool can be applied to diverse settings to support a dedicated focus on human dimensions of care, such applications will add to evidence about utility and transferability.

Secondly, HCAT can act as a conceptual guide for empirical research that explores what really matters to people in different settings. Furthermore, a values framework that takes account of what can contribute to a sense of being human is useful to enrich the synthesis of existing qualitative research (across a number of care contexts and clinical settings) to provide an extensive evidence base that coherently translates existing qualitative evidence into tangible practice directions.

Finally, practice is a human activity that requires a certain kind of humanly sensitive attunement. Whereas the lifeworld is a holistic foundation to this attunement, specifically, HCAT offers new coherent directions for what constitutes caring actions in healthcare contexts. While caring has been difficult to define, HCAT offers behaviours that attend to what matters to people on the receiving end of care. We suggest that such an assessment tool comprising theoretically-led experiential items, about what makes people feel more, or less than human, offers some improvements on available assessments of care.

This questionnaire is designed to assess what things your current work environment enables you to do to focus on the human aspects of care.

Please read over the following questions and consider each item in terms of, on average, how often your current work environment enables the following behaviours. Please then circle your answer on the scaled response between 1 – 5, e.g. with 1 being ‘always’ and 5 being ‘never’.

My work environment enables me to	Always, Most of the time, Some of the time, Rarely, Never				
	1	2	3	4	5
1) Attend staff development events	1	2	3	4	5
2) Ask the patient how they assess their own health	1	2	3	4	5
3) Remember small details about patient’s personal stories	1	2	3	4	5
4) Ask patients about their expectations of care and treatment	1	2	3	4	5
5) Make sure patients know your name and role	1	2	3	4	5
6) Give patients the confidence to manage their own conditions	1	2	3	4	5
7) Use non clinical language when talking with patients	1	2	3	4	5
8) Where safety concerns allow, adapt the environment to make it as homely/personal as possible	1	2	3	4	5
9) Use patients preferred name	1	2	3	4	5
10) Ask patients how it is going for them	1	2	3	4	5
11) Where possible offer patients choices about what happens to them next	1	2	3	4	5
12) Show patients you are pleased to see them when they arrive for treatment	1	2	3	4	5

13) Consider how the environment (e.g. noise, images, smells, friendliness) could make patients uncomfortable	1	2	3	4	5
14) Help patients to stay close to their own everyday routines	1	2	3	4	5
15) Ensure that the patient has a means of communication with a named health service provider on discharge	1	2	3	4	5
16) Try to involve significant others as the patient wants	1	2	3	4	5
17) Assure patients that they can always call for advice	1	2	3	4	5
18) Try to find out information that the patient wants on their behalf	1	2	3	4	5
My work environment enables me to	1	2	3	4	5
19) Be prepared to change direction if treatment is not working for the patient	1	2	3	4	5
20) Notice what can support patients to take a role in care and treatment decision making	1	2	3	4	5
21) Consider how the surroundings (e.g. noise, images, smells, friendliness) makes patients feel comfortable	1	2	3	4	5
22) Keep patients informed at regular intervals when they are awaiting results	1	2	3	4	5
23) Provide information about how the service works (meal times etc.)	1	2	3	4	5
24) Remember small details about patient's personal care preferences	1	2	3	4	5
25) Notice barriers that can get in the way of patients feeling welcome	1	2	3	4	5
26) Consider how patient's future aspirations may be affected by their current treatment.	1	2	3	4	5
27) Show patients and family members the hospital complaints policy	1	2	3	4	5

28) Encourage patients to support each other, wherever possible and when wanted	1	2	3	4	5
29) Actively seek promotion	1	2	3	4	5
30) Give patients the skills to manage their own conditions	1	2	3	4	5
31) Ensure families and friends feel welcome	1	2	3	4	5
32) Understand the everyday consequences of treatments or care plans, which have to be carried out by the patients themselves	1	2	3	4	5
33) Update patients on treatments regularly	1	2	3	4	5
34) Consider how generic treatment pathways fit with the individual patient	1	2	3	4	5
35) Introduce patients to others who share their condition, when wanted	1	2	3	4	5
36) Notice what affects your patient's mood	1	2	3	4	5
37) Encourage other staff to introduce themselves by name and role	1	2	3	4	5
38) Help patients understand the changes that may be happening to them	1	2	3	4	5
39) Seek out how care could be adapted to suit the individual patient's situation	1	2	3	4	5
40) Encourage patients to complete patient satisfaction forms	1	2	3	4	5
41) Consider how the care setting we operate in can be initially unfamiliar to patients	1	2	3	4	5
42) Create a welcoming environment	1	2	3	4	5
	1	2	3	4	5

My work environment enables me to					
43) Notice barriers that can get in the way of families feeling welcome	1	2	3	4	5
44) Seek out flexibility in the system to respond to patients priorities	1	2	3	4	5
45) Offer support to patients moving through a system they are unfamiliar with	1	2	3	4	5
46) Recognise the importance of a regular review of care with the patient	1	2	3	4	5
47) Be able to set clear goals	1	2	3	4	5
48) Be able to support colleagues	1	2	3	4	5
49) Read a professional journal frequently	1	2	3	4	5
50) Show visitors how to use soap dispensers	1	2	3	4	5
51) Have the time to reflect on my own feelings	1	2	3	4	5
52) Consider how the environment (e.g. noise, images, smells, friendliness) could make patient's significant others feel uncomfortable	1	2	3	4	5
53) Show that you want to know about patients fear about their situation	1	2	3	4	5
54) Find ways to help patients stay in touch with important things from their everyday life	1	2	3	4	5
55) Consider the patients feelings about being isolated	1	2	3	4	5
56) Have a sense of a human connection with the patient	1	2	3	4	5
57) Ask patients how they are finding their journey through care	1	2	3	4	5
58) Be aware of the physical impact on me, of giving bad news	1	2	3	4	5
59) Show patients where they can find peaceful spaces	1	2	3	4	5

60) Explain to patients where there is no flexibility in the system and why	1	2	3	4	5
61) Take steps to put patients at ease	1	2	3	4	5
62) Focus on making the patient feel at home	1	2	3	4	5
63) Feel supported by colleagues	1	2	3	4	5
64) Help patients feel comfortable enough to ask questions	1	2	3	4	5
65) Check all equipment is accessible before seeing patients	1	2	3	4	5
66) Notice patients at particular risk of isolation	1	2	3	4	5
67) Support patients to have a say in their care or treatment	1	2	3	4	5
My work environment enables me to	1	2	3	4	5
68) Notice what makes the patient feel energised	1	2	3	4	5
69) Make sure patients are treated by a named or consistent member of staff'.	1	2	3	4	5
70) Take an interest in what patients tell me about how they like things done	1	2	3	4	5
71) Be aware of the anxiety patients can experience when waiting for results	1	2	3	4	5
72) Regularly check that treatment is going okay from the patient's point of view	1	2	3	4	5
73) Frequently ask patients how they are	1	2	3	4	5
74) Consider the different responses patients can have to the same illness or condition	1	2	3	4	5
75) Provide care that is not only technical/task focused	1	2	3	4	5

76) Appreciate that how a patient sees the severity of their illness or condition may differ from my own	1	2	3	4	5
77) Gain experience treating a variety of cases	1	2	3	4	5
78) As far as possible facilitate contact with important people in the patient's life	1	2	3	4	5
79) Create a sense of calmness (when possible)	1	2	3	4	5
80) Try to see the person behind the illness or condition	1	2	3	4	5
81) Be aware of the personal meaning any bodily (physical) changes for the patient	1	2	3	4	5
82) Give patients time to talk about their emotional response to their illness/condition	1	2	3	4	5
83) Provide patients with information on peer support	1	2	3	4	5
84) Consider how the surroundings (e.g. noise, images, smells, friendliness) makes staff feel comfortable	1	2	3	4	5
85) Keep updated on the latest policies in your field	1	2	3	4	5
86) Understand what prevents patients asking for help/information	1	2	3	4	5
87) Be aware of the physical impact of bad news for the patient	1	2	3	4	5
88) Acknowledge, with each patient, the fear that can come with health conditions	1	2	3	4	5
89) Offer sensitive explanations on what is happening (now and in the future)	1	2	3	4	5
90) Focus on what is of concern to the patient (even if outside or unrelated to treatment)	1	2	3	4	5
91) Notice what makes the patient feel tired	1	2	3	4	5
My work environment enables me to	1	2	3	4	5
92) Show that you want to know 'what it's like' from the patient's perspective	1	2	3	4	5

93) Consider the emotional aspects of the patient's treatment or condition	1	2	3	4	5
94) Understand what prevents staff asking for help/information	1	2	3	4	5
95) Discuss each patient as a person (not just health condition or case) when sharing information with other health professionals	1	2	3	4	5
96) Notice how staff behaviours could create embarrassment, shame or vulnerability, during treatment	1	2	3	4	5
97) Update your training regularly	1	2	3	4	5
98) Be organised when booking annual leave	1	2	3	4	5
99) Consider how the surroundings (e.g. noise, images, smells, friendliness) makes families or significant others feel comfortable	1	2	3	4	5
100) Where possible, to help patients to have some meaningful possessions close at hand	1	2	3	4	5
101) Repeat information about what is happening to patients regularly	1	2	3	4	5
102) Care about the wellbeing of my colleagues	1	2	3	4	5
103) Build trusting relationships with patients and their significant others	1	2	3	4	5
104) Check that patients are comfortable	1	2	3	4	5
105) Encourage patients to ask what is happening and why	1	2	3	4	5
106) Think of the patient as a person and more than just a body	1	2	3	4	5
107) Make space to listen to the patients worries, even if they can not be resolved	1	2	3	4	5
108) Notice what makes the patient feel relaxed	1	2	3	4	5

109) Be aware of hospital dignity/health and safety/ cleanliness (i.e. any type of policy) policy	1	2	3	4	5
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Thank you for your time completing this questionnaire

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