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College of Radiographers Doctoral Fellowship 009

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Title: Exploring compassion and compassionate behaviours in cancer care: A mixed methods study

Aims:

1. To generate a shared healthcare definition of compassion within the context of radiotherapy.

2. Identify how compassion is conceptualised and displayed within a radiotherapy healthcare context.

3. Develop a theoretical model of compassion to optimise understanding and aid teaching and development in healthcare pedagogy.

Hypothesis:

As this project is a mixed methods study hypothesis testing is not the aim of the research.

Primarily the study is exploratory in nature and the following research questions will be addressed in the study:

From the perspectives of patients, students and clinical staff;

1. What do they understand compassion to be?

2. How do they believe compassionate behaviours are demonstrated?

3. How do they think compassion should be taught to pre-registration radiotherapy students and how should the compassionate ability of students be assessed?

Outcomes:

Creation of knowledge:

1. Identification of what patients and carers, student therapeutic radiographers and therapeutic radiographers think compassion is and what behaviours are associated with its practice.

2. A definition of compassion which has been co-created by the three participant groups and that is situated in a healthcare setting.

3. An evidence based curriculum for Higher Education Institutions that will aid the development and enhancement of compassion and compassionate practice of pre-registration student therapeutic radiographers.

4. An increase in the compassion delivered by health professionals and subsequently that experienced by patients, aiding the culture of patient-centred care.

Background to the Project:

The necessity to develop and subsequently utilise caring and compassionate behaviour within the healthcare workforce is central to radiographers' professional practice [1] and is congruent with the core values of the NHS Constitution [2]. Compassion is a key recommendation of health legislation [3-7] this has been amplified following a number of high profile incidents in the UK where inadequate care and compassion reduced the quality of life of patients, with some instances resulting in death [8-10]. Patient experience is another important facet of UK Government policy [13,14] and compassionate behaviours may be regarded as synonymous with patient centred care [12].

Tackling the compassion deficit is placed at the centre of government initiatives [3, 7,8, 15-17]. These advocate both Higher Education Institutions (HEI) and the NHS should instil and develop core caring and compassionate skills in the health workforce. Despite insisted policy there continues to be a surfeit of failings which are all too often considered to be the inevitable [18]. This continuance raises questions regarding the ability of NHS Trusts, and service delivery managers alongside the individual employees to understand, interpret and implement policy recommendations at a local level.

The policies themselves fail to define compassion, how it should be displayed, nor do they testify how to develop compassionate skills or behaviours in health professionals [3-7, 13, 14, 19-20], or clinical practice. The six C’s advocated by the Department of Health’s (DoH) Compassion in Practice document have become a fundamental part of healthcare structure and now, the cornerstone of values based recruitment [7]. Compassion, alongside Care, Competence, Communication, Courage and Commitment is one of six core values which registered health professionals and supporting staff must possess and display throughout their daily practice. When publishing a policy whose primary focus is compassion one would presume it would provide meaning and clarification, instead it indistinctly describes compassion as "how care is given through relationships based on empathy, respect and dignity” [7]. Instead of a definitive meaning providing clarification, this definition merely aids confusion, simply providing a 'buzz-word' list of values without explanation. Neither pre nor post Francis policy [8] contradict this trend, providing equally ambiguous definitions [21], no definition at all [3,6] or simply referring to the definition provided by the DoH [5].

Concepts, such as 'compassion', are subjective, and are traditionally argued to be shaped and influenced by the environment and the objects in which they are situated [22]. Dictionary definitions are in abundance [23-29], but these frequently include terms such as pity, empathy and sympathy, each of which have their own definitions, creating confusion about its true meaning.

The concept of compassion is commonly researched but the focus is upon identification of what health practitioners perceive compassion to be [30-32]. Research fails to validate if these are the behaviours which patients themselves perceive as compassionate or behaviours they wish to see in professionals that are caring for them. Resultantly no definition of compassion exists where its meaning has been considered and co-created by both those who are delivering and receiving it.

Preliminary data:

Compassion and compassionate care have become a prominent and debated topic within healthcare with an abundance of publications, opinion papers and counter arguments flooding the academic arena in addition to the tabloid and media coverage. With a few exceptions, most published literature however concentrates heavily on the nursing and medical professions, often failing to reflect the contribution to a patients' pathway and care radiographers have.

Bolderston et al. (2010) investigated what therapeutic radiographers (n=27) understood by the terms care and compassion [30]. Focus groups identified these concepts were seen primarily as a part of supportive relationship with the patient but they were unable to agree if the technical aspects and procedures were considered a part of caring. The research failed to validate if these are the behaviours which patients themselves perceive as compassionate or behaviours they wish to see in professionals that are caring for them in the radiotherapy department. In their research, Halkett & Kristjanson (2007) conducted semi-structured interviews with breast cancer patients (n=34) [33]. They found therapeutic radiographers play a central role in enabling patients to achieve a sense of emotional comfort. They acknowledged that although therapeutic radiographers play a technical role they need to remain aware of their role in providing patient care and take appropriate steps to ensure that they can assist patients in feeling comfortable during their treatment.

Both studies identified there is a lack of clarity around the meaning of compassion in the professional role, there is confusion as to whether the fundamental role of delivering radiation is part of compassionate practice and fail to examine whether patients agree and perceive this as compassion or compassionate behaviour.

A pilot focus group undertaken as part of PhD development with cancer patients and carers
(n=5) reviewed a number of traditional dictionary definitions of compassion. Participants responded strongly to the words and phrasing of these definitions in particular "sympathetic pity and concern for the suffering or the misfortune of others" [23] . Participants deemed this as negative, having an explicit dislike to the word pity, expressing that "if I want someone to feel compassionate towards me I don't want them to pity me".

A recent concept analysis [34] completed as part of this research distinguished compassion in healthcare from other contexts and identified it as being composed of five attributes: Recognition, Connection, Altruistic desire, Humanistic response and Action. Empirical referents; the phenomena whose presence demonstrate the defining attributes and help determine the occurrence of the concept [35] for compassion can be structured into three categories: non-verbal, verbal and professional practice. Although outlining associated meanings and behaviours which aid our understanding of compassion, the findings identified the complexity of the term and subjective nature in which it is displayed and in turn perceived. The work also highlighted there is no one agreed definition of compassion, those which have been developed have been given an assigned meaning based on previous literature and dictionary definitions as opposed to being developed within an appropriate healthcare context.

Methodology

The research is following an exploratory sequential mixed methods design [11] (Figure 1).

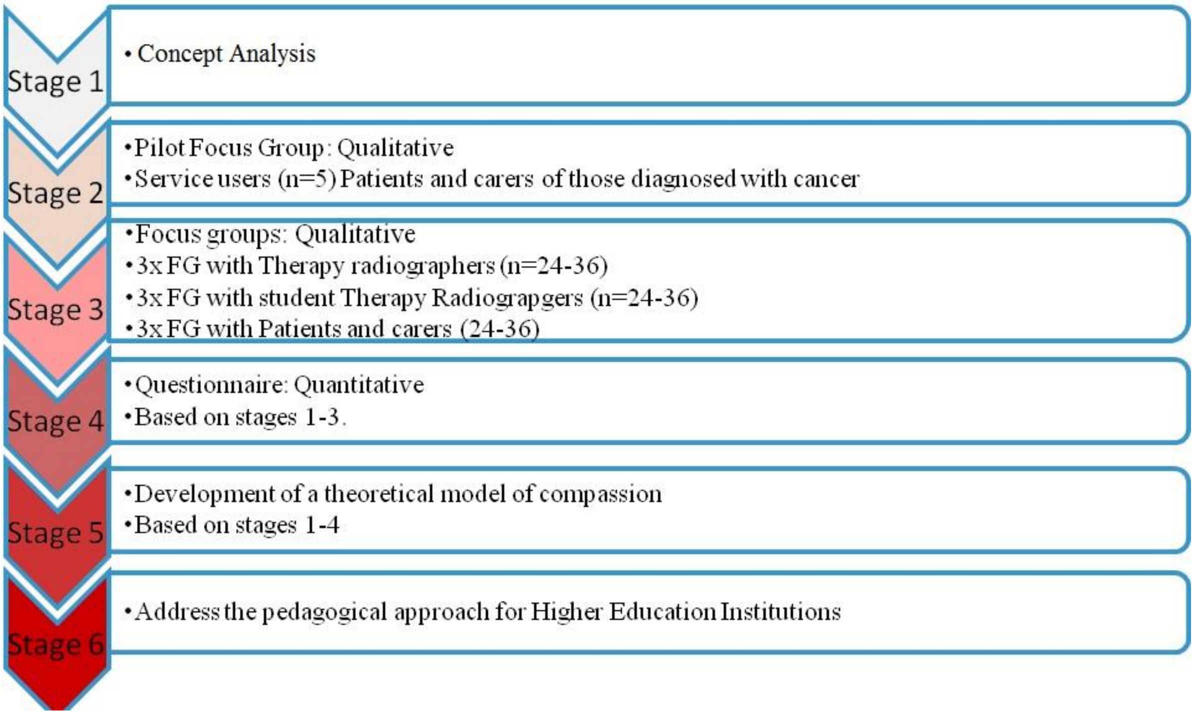

Figure 1: Flowchart of sequential mixed methods design.

Stages:

One:

A concept analysis used the eight stage process by Walker and Avant [35] to gain an understanding of the meaning of compassion within a healthcare context. (RQ1)

Two:

A pilot focus group (FG) explored service users* (SU) perspectives of the current definitions of compassion. It addressed the feasibility by providing a 'trial run' [36] and pre-testing of the FG method [37], allowing the researcher to identify possible problems and adaptations. It also obtained preliminary data and feedback from the SU about their experiences of involvement in this research format. (RQ1&2)

* (patients and carers who have received a previous diagnosis of cancer)

Three:

FG's at three UK NHS radiotherapy departments will be conducted separately with therapeutic radiographers (TR) and patients and carers (PaC). Three FG with student therapeutic radiographers (STR) will be undertaken at the host institution. (RQ1&2)

Four:

Findings of stages 1-3 will be collated to co-develop a questionnaire with the participant groups, aiming to survey a wider proportion of the population of PaC, TR and STR. Where appropriate, questions will be generated directly from statements made within the FG's allowing for the original findings to be represented and not diluted or amalgamated in the design process. The aim is to identify if the answers generated by the FG are generalizable to the wider population aiding the validation of findings from the FG.   (RQ1&2)

Five:

Based on the findings of stages 1-4:

A theoretical model of compassion and compassionate behaviour will be co-constructed with the participant groups.

The groups will discuss what methods of teaching and assessing student's compassionate abilities could be used. (RQ1, 2, 3&4)

Six:

Based on the findings of stages 3-5, stage 6 will begin to address in preparation for post-doctoral research the pedagogical approach to teaching compassion HEI's should adopt to ensure they are producing graduates who meet workforce requirements. (RQ3&4)

Philosophical stance

The research will undertake a social-constructivist methodology as the research questions will be explored based on the perspectives of the three different participant groups and the individuals situated within them, aiming to derive a shared meaning of compassion.

Sampling and recruitment strategy

Each potential participant will receive a study information pack which will comprise of an invitation letter, participant information sheet; consent form and study reply form, with a stamped addressed envelope. Each of the three categories of participants will have planned total participant number of n=15-36 [38-41].

Stages:

Two:

Used a convenience sample as SU (n=5) were invited based on their previous diagnosis of cancer and were currently SU at the host institution.

Three:

a) All pre-registration Radiotherapy & Oncology students (n=180) across the 2 year PgD and 3 year BSc programmes at the host institution will be invited to take part.

b) PaC carer recruitment will be through non NHS support and information centres affiliated with the three NHS radiotherapy departments. The Principle Investigator (PI) will be asked to give potentially eligible participants the study information pack, the researcher or PI will contact them once a study reply form is received indicating their willingness to take part.

c) All TR employed at the three radiotherapy centres will be invited to attend. The PI will contact those who have expressed an initial interest in taking part and provide them with an information pack.

Four:

Sample size calculations are not required as the questionnaire aims to explore the opinions of participants understanding of compassion rather than quantifying how many of the participant population agree with the findings of stage 1-3. Approximately 600 questionnaires will be distributed. Participants will be recruited using the recruitment strategy outlined in stage 3. Additionally,

i) Patient support groups local to the author and PaC involvement forums will be used to widen the participant pool. The questionnaire will be provided either online or in printed format to aid compliance.

ii) Existing contacts with radiotherapy departmental managers will be utilised to broaden the number of TR invited to participate.

Data collection and analysis

Stages 2 & 3.

FG are compatible to the interpretative format of the research focus [38-41] and will be conducted semi-structured with use of a FG guide, audio recorded and transcribed in verbatim with notes being made by both the facilitator and moderator to gain rich secondary data. A framework [42] method will be used in the analysis of the FG transcripts and coding will be carried out using QUIRKOS [43].

Stage 4

There are no questionnaires available which investigate understanding of compassion, therefore a bespoke questionnaire will be co-designed based upon the findings of stages 1-3. All coding and analysis will be carried out using SPSS 22.0 [44]. A convergent/divergent matrix will be created which will allow for identification of opposing/conflicting quantitative data and patterns across all cases [45].

Ethical Considerations:

University Research Ethics Committee approval has been obtained for stages 2-4. Health Research Authority (HRA) approval has been obtained and local Research and Development approvals (R&D) will be obtained for the three NHS Trusts.

All participants will be required to provide informed consent, which will be obtained by the researcher or PI who are Good Clinical Practice (GCP) trained. To maintain confidentiality and anonymity all corresponding documents will be stored safely and securely within a locked cabinet on the University premises. Data will be anonymised and stored in a password protected computer that is backed-up each evening on a secure network.

Further considerations:

Stage 2:

There was potential for an unequal power balance, with the SU participants and the researcher due to the dual role of facilitator and recruiter to academic delivery. This was addressed by the participant information sheet explaining the FG is voluntary, not related to their academic involvement and if they did or did not attend or any opinions expressed would have no bearing over their future involvement with the institution. Participants were informed no payment would be received.

Stage 3:

a) STR will be informed that the choice to participate (or not) will not affect their academic training, grades or continuation on the programme. Due to the nature of the professional health courses and academic requirements, students are likely to have a good understanding of the principle of autonomy and informed consent and so do not naturally fall into the Mental Capacity Acts category of vulnerable participants [46]. However, as their lecturer conducting the research there may be a perception of coercion for them to participate due to the multiple roles and the unequal power balance this creates. Information and communication will be open and honest throughout the whole process, this transparency will extend to other lecturers and colleagues involved with the programme allowing for students to be able to discuss with colleagues. All elements and timings of the study are designed to create minimal impact upon the students learning experience.

Stage 4:

Participants will complete the questionnaire anonymously; any identifiable data included by the participant will be removed by the researcher.

Reliability and validity

- Feedback on the acceptability and utility will be obtained during the co-production of the questionnaire.
- The questionnaire will be pilot tested to explore formatting and address any distribution issues which may influence response rates [47].
- Face validity of the bespoke questionnaires will be assessed by the QQ-10 instrument [48].

Minimising Bias

i) A research journal will be kept throughout the study; to provide an audit trail of the developing themes and to support the development of a reflexive account to record and review personal experiences and prior assumptions.

ii) Peer debriefing with PhD supervisors will ensure the themes come from the data itself ensuring researcher integrity is maintained.

iii) Member checking within the FG both within and post session to review the authenticity of the themes developed.

iv) Triangulation of the themes found within the literature with the FG and co-creation of the questionnaire to ensure it reflects the views of the FG participants not those of the researcher.

Potential problems and contingency plans

- The focus groups shall be considered quorate if at least 5 participants are in attendance, as a contingency for attrition/non-attendance over-recruitment will occur.

- If participant numbers are not met, the researcher deems saturation has not been achieved or further exploration of data is required additional focus groups may be undertaken.

- To overcome issues caused by staff sickness or unavailability of a moderator or patient representative for the focus groups, a named reserved will be identified to step in if required.

- Participants will be provided with time at the end of the FG to 'debrief' and ask any questions. Any participant who indicates the FG have evoked an emotive response will be signposted to the appropriate scheme of support.

User Involvement plans:

The project has been developed in conjunction with service users at the host Institution, with consultations occurring at key stages of its design including preliminary idea generation and proposal development. The feedback obtained during the pilot focus group has been built into the research proposal. Patients and Carers as user representatives are at the centre of the design and data collection method utilised in this research and it was therefore essential to ensure this was developed in unison to ensure the methods were deemed appropriate and were something they were supportive of being involved with.

The researcher has worked closely with the North Trent Cancer Research Network Consumer Research Panel (NTCRNCRP) and prior to HRA and R&D submission, the proposal and all participant information was reviewed by the panel and amended as required.

Further user consultation will occur:

- On completion of the focus groups, representatives from each of the participant groups will work alongside the researcher to develop the questionnaires.

- NTCRNCRP is to review the questionnaire and supporting participant information prior to distribution.

- On completion of data analysis, participant representatives will be invited to review the findings and work with the researcher to generate a co-created definition of compassion.

Potential impact

A co-created definition and theoretical framework will provide 'real life' meaning to compassion, allowing NHS Trusts to interpret and implement health care legislation [7, 13-15, 19] in to 'real world' practices.

A pedagogical approach will present HEI’s with an opportunity to develop their curriculum to increase the likelihood of students exiting programmes with skills that will ensure good quality patient care.

Increasing the compassion delivered by health professionals and subsequently that experienced by patients will aid the cultivation of patient centred care, reducing the shortcomings experienced by patients undergoing care and treatment within the NHS.

Dissemination Strategy

Harmsworth & Turpin's [49] three platforms will create a comprehensive plan, targeting a wide audience. 'Dissemination for Awareness' will be at a local level at the Host institution, the topic is important to wider Allied Health Professionals (AHP) with the values connected to compassion being inherent for all HEI health care courses therefore presentation at the Faculty led Learning Teaching and Assessment annual conference would be a valuable forum.

'Dissemination for Understanding' and 'for Action' will include presentation at European Society for Radiation Oncology (ESTRO), American Society for Radiation Oncology (ASTRO), Society & College of Radiographers (SCoR) annual radiotherapy conference and SU Involvement conferences intending to reach academic and clinical professionals involved both in the training of radiotherapy and AHP students and the treatment and care of cancer patients. The topics of compassion, health care professionals and co-creation, creates a wider audience. Therefore, in addition to publication in SCoR Radiography journal, Nurse Education Today and specialist Radiotherapy and Oncology Journals will provide an acclivity for each appropriate facet of the study.

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