Professional insights from an analysis of patient accounts of radiotherapy treatment

Person-centred care in practice

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Introduction

Person-centred care is a prominent concept in healthcare and radiography[1] but it is less obvious what this means in practice[2]. The patient experience literature in radiotherapy is predominantly about the impacts of radiation during and after treatment and related informational needs. A smaller body of work considers therapeutic radiography as a sociotechnical system, where the patient experience is formed by interpersonal interactions with the radiographer and the treatment environment[3-7]. Published accounts of the direct patient experience, which embrace the potential for mutual misunderstandings or lack of connection attendant in radiotherapy treatment, are rarer still[8].

Data from the National Cancer Patient Experience Survey (NCPES) suggest high levels of overall satisfaction with cancer services[9,10] and radiotherapy services[11,12]. Population-level data, however, tend to generate more positive responses than in-depth exploration of specific experiential events and can diminish minority voices[13]. NCPES quantitative data do indicate the need for effective personalisation of cancer care[14] but are typically not sufficiently sensitive to enable service providers to understand in depth the issues that we know influence patient satisfaction, such as person-centred care[15]. Standards for learning from service user feedback therefore recommend that surveys are complemented by the patient voice, including patient stories[16]. Patient stories capture the interest of staff, enable them to view their services from the patient's viewpoint and thus see where services might be improved in response[13,17].

This paper analyses detailed accounts from two people who have undergone radiotherapy. The aim was not to concentrate on the negative but to seek understanding of the meanings attributed to radiotherapy treatment where experience was not optimal. This enables a contemplation of deeper thoughts/feelings that may shape human behaviour in this context.

Methods

The analytical approach was a qualitative document analysis based on the approach described by Morgan[18]. Document analysis is an established method (more so in the social sciences and arts) that uses a systematic approach to infer deeper meaning and generate understanding in existing textual sources[19]. Typically, two or more data sources enable similarity and difference to be identified.

Data selection

Data selection is a key decision in document analysis[18]. The handling of the four factors that guide selection – authenticity, credibility, representativeness, meaning[20] – is outlined in Table 1.

Authenticity	Primary sources with a named author, date & copyright information
Credibility	Direct first-hand patient accounts of radiotherapy treatment with the motive of expressing honest lived experiences
Representativeness	Detailed accounts of a course of modern external beam radiotherapy treatment from the patient point-of-view
Meaning	Content with relevance to the current paper's aim with sufficient depth for literal and interpretative meaning

Table 1 Handling of the four factors that guide source selection for document analysis

The selection strategy outlined in Table 2 was used to scope the availability of eligible published documents. Databases were chosen to incorporate nursing, allied health, biomedical and social science, and media sources.

Databases	MEDLINE by Ovid; Cumulative Index to Nursing & Allied Health Literature (CINAHL); Applied Social Sciences Index and Abstracts (ASSIA); Pressreader
Key words	'radiotherapy' OR 'radiation therapy' AND 'patient experience' OR 'patient stories'
Dates	2000 to 2023
Inclusion	Direct patient accounts of radiotherapy treatment deemed to have authenticity, credibility, representativeness, meaning
Exclusion	Studies using quantitative measures; studies focused on patient anxiety or physical side effects; researcher analysis of qualitative data

Table 2 Search strategy for a preliminary scope of eligible documents

The title and abstract of 263 results were checked against eligibility and one article retained[8]. A second eligible document[21], identified through a professional network, was purposely selected because it directly met the selection criteria in Table 1 and provided variation in author context (see Table 3).

Sylvie Leotin (2020)[8]	*An insider view of the cancer radiation experience through the eyes of a cancer patient* (article published in Journal of Patient Experience)
Author Perspective[1] Clinical details	• Self-described as 'Passionate about the human experience and fostering human well-being, she consults and teaches workshops to help organizations address unrecognized human needs, and increase patient and customer well-being • Treated in US for curative breast cancer
Jenny Diski (2016)[21]	*In Gratitude* (a memoir written after diagnosis of inoperable cancer)
Author Perspective Clinical details	• Acclaimed UK author of fiction and non-fiction. Her writing has been characterised as idiosyncratic, honest, opinionated, & transgressive • Treated in UK by sequential chemo-radiation for lung cancer in 2014. Jenny Diski died a week after publication

Table 3 Data sources and personal and clinical perspective of the authors

Data analysis

A thematic analysis was undertaken according to Braun and Clarke's framework[22]. Data was coded inductively from the documents without a pre-existing coding frame. Initial descriptive codes were considered for relevance before interpretative codes were generated that enabled deeper meaning to be inferred. Themes were developed iteratively, which represented the essence of grouped codes. Themes were checked and rechecked for overlap and omission.

Reflexivity

As a single researcher, it was important that a reflexive approach to documentary analysis was adopted; an approach that views the researcher's subjectivity, characteristics, and history as a resource, not a limitation[18,22]. I have previously spoken at professional events about my/the dual experience of radiotherapy as a patient and professional[23]. My perspective (and motivation) as the writer here is as someone who has delivered many fractions as a therapeutic radiographer and who has personally received two courses of radiotherapy. This experience was drawn upon to aid credible coding. Uncertainties in analysis were recorded to allow codes to be split, combined, or renamed to reflect an evolving interpretation. The interpretive process, grounded in longstanding reflection and reading, led to several sociological concepts that provided a lens for inferring meaning in the patient accounts and maybe, by extension, my own experiences.

Findings

The selected documents and their author contexts are characterised in Table 3.

"JD" and "SL" denote Jenny Diski and Sylvie Leotin, respectively. "Radiographer" denotes a therapeutic radiographer or radiation therapist. Data analysis generated two themes within a meta theme of "divides".

Theme 1: human vs machine

A core perception was of a treatment milieu that denied the humanity of patients. Even with distinct settings, both authors described an uncomfortably cold room and matching emotional temperature that left Leotin *"… bewildered by the gap in understanding of human needs…"* The required/desired moment of human connection was not offered:

"'Next time I won't come get you. Go straight to the dressing room, put on a gown, and wait in the waiting area I'll show you.' That's all he said. Then left me to figure out the rest. I was stunned by the coldness of this first reception." SL

With a comparable absence of human connection, the treatment gown, and its presentation as something valuable that was hers to keep through treatment, became a tangible focus of irritation for Diski:

"The smock kept me modestly covered for approximately 20 seconds between entering the radiotherapy room and lying down on the bench. It was to ensure decorum I supposed. A leaflet about the treatment ended with an assurance that maintaining my dignity was important to the team." JD p.123

She soon stopped using the gown as, to her, it did not provide dignity: it was a dehumanising formality that rendered her hidden as a person and thus enabled her to become seen as a departmental part:

"My dignity was left at the door of the treatment room each day, not because my breasts were revealed but because as soon as I entered I became a loose component, a part the machine lacked, that had to be slotted into place to enable it to perform its function." JD p.123

This dehumanised sentiment is cemented by the perceived attitude of the radiographers as being focused on the technical, the machine, and workflow: not interested in human needs, interested only in solving a problem of machine-space geometry – *"… nudging my inexact boundaries into co-ordinated perfection"* (JD p.124) – while ignoring the person that inhabited that space. The daily

identity check represented a rare staff-patient interaction, but this became seen as an act that enabled radiographers to reduce the person to a number. Leotin similarly deplored a depersonalised experience:

"It chilled my spine. Lots of efforts had been placed into maximising output. Less so on ensuring a conducive experience for cancer patients." SL

This was despite the presence of a dedicated patient experience department in the treating hospital, whose efforts she believed *"… fail to go deep enough to understand the root causes of patient distress."*

Theme 2: machine vs human

Maybe unsurprisingly, the authors also concentrated on the machinery of radiotherapy. When Leotin explains the required cognitive effort to shift from viewing the treatment as a threat to a therapy, *"It didn't help that the radiation suite looked like a torture museum I had visited long ago."*

Even Diski's eloquence struggled to describe a standard linac, though amusingly *"The designer for the Terminator movies would have wept to see it."* (JD p.125). She describes an incomprehensible machine with a mirrored face and three blank arms, whose movements and sounds remained unfathomable and induced irrational thoughts of its collapse on to her at any moment. Crucially:

"No one told me what was happening, and before the technicians went into their safety room it didn't seem possible to interrupt their measuring minds to ask what, exactly, it was doing as the arms moved, or didn't." JD p.126

Discussion

This section uses an explanatory sociological interpretation of each theme to propose mechanisms that may underlie behavioural responses to the radiotherapy context.

Theme 1: human vs machine. Interpretation – the total institution

The contention advanced (in different words) by both Diski and Leotin is that the failure to recognise the patient's humanity was likely rooted in people acting within institutional constraints, rather than deficiencies in individual radiographers, which seems broadly correct to me. Someone attempting to critically evaluate how the institution can shape patient-centred practices may find insight in Goffman's theory of the "total institution"[24]. A total institution is *"a place of residence and work*

where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life"[25]. An outpatient radiotherapy centre will not be as closed a system as some institutions but it does fulfil key characteristics of there being the managed (patients) and the managers (staff). The two groups are kept separate by ritualistic rules and behaviour that leverage an informational imbalance to reduce individual patient agency. Formalised institutional requirements are used to diminish personhood, particularly admissions routines that allow a person to play only a limited, standardised, preordained role[26]. Diski hates being forced into playing a preordained role, brilliantly describing the whole cancer experience as an act of pantomime, implying its own set of inescapable calls and responses if one is to be a good patient. Given these ideas, it is noteworthy that the de-personalised radiotherapy experience did not fare well compared with Diski's earlier experience of chemotherapy. She felt that the nurses in that setting always dealt with each patient as an individual, however busy, suggesting that the technical and interpersonal aspects of therapeutic radiography can be usefully rebalanced[27].

Theme 2: machine vs human. Interpretation A – machine as a boundary object

Evidence suggests patients feel that an understanding of how radiotherapy works is more important than staff believe it is for them[28]. A relevant sociological concept identified in the data interpretation process was a *boundary object*: *"Boundary objects are entities that enhance the capacity of an idea, theory or practice to translate across culturally defined boundaries, for instance, between communities of knowledge or practice"*[29]*.* The boundary here being the divide between lay (patient) and professional (radiographer) communities of knowledge. Such demarcations disrupt knowledge transfer but may be bridged by a boundary object, which is a liminal object common to the frames of both communities[30]; the boundary object, in this case, is the linac. Actively rendering the linac comprehensible to the patient may soften the boundary enough to encourage their embrace of the unfamiliar environment and find connection and common purpose with the radiographer. This working collaboration functions even as both sides hold distinct social meanings and understandings of the boundary object[31]. Conversely, the incomprehensible or alien object represents a barrier that isolates the less knowledgeable party and (in our case) allows their imagination to fill in the blank with frightening scenarios of mechanical or radiation injury. In other words, an explanation of the technology we use can form the basis of a shared human connection that is meaningful to the patient experience and can reduce reported anxieties in the radiotherapy department[32].

Theme 2: machine vs human. Interpretation B – existential dread

A second sociological concept with relevance to an isolated, dehumanised experience of radiotherapy is existential dread[33]. Diski was still receiving active care at the time of writing, although aware of the incurability of her cancer. Reference to the "*danse macabre*" of the linac as it delivers its "*death rays*", and Leotin's descriptions of "*rail thin*" bodies, the "*primal*", the "*void*" and feeling "*lucky to be alive*" imply a close personal relationship with the threat of death.

A weighty claim from 1970s cultural anthropology is that human activity has always been driven by a basic need to escape mortality – acts of self-preservation and cognitive denial of one's inevitable end both serve to form a divide between the living and those at or nearer death[33]. A more recent extension of this idea, terror management theory[34], provides a heuristic device to consider how this phenomenon might play out in a radiotherapy department. The cancer patient moves into a new state where the threat of death is more pressing than before, but the radiographer instinctively wants to stay with the living by avoiding or distracting from this state. This human instinct for life may play out in laudable subconscious behavioural responses, such as forming an identity as a hard-working radiographer who sacrifices themselves for the greater good at work, maintaining a busy social life or through having children. Despite our professional training and inclinations to treat people equally and without stigma, the instinct for life may also manifest as a subconscious need to separate from the "semi-living". The patient's existential dread presents a threat, against which the radiographer's defence would be to distance, denigrate or dehumanise.

Implications for practice

Whether or not the preceding existential reading sounds fanciful, one countermeasure against a psychic staff-patient divide would be to consider death more directly in therapeutic radiographer education and training. Arguably even the biological mechanisms that cause death from cancer remain somewhat opaque as the end typically happens in another time and place.

Appropriate explanations of the linac to every patient can be considered as more than giving information. The discussion of a shared object provides an opportunity for the patient to enter our frame and us to enter the patient's frame. That is, to develop connection and bridge divides. Fortunately for radiographers seeking to develop a supportive human connection with their patients, the value of small, relational, and communicative gestures that pay attention to dignity and kindness are emphasised in the literature[4,27]: actions that often do not take resources or even great empathetic skill but do need to be centred on the person and their individual needs. Grander technical developments in radiotherapy can also be implemented so as to foreground how the

clinical process will be experienced by the person at the sharp end, rather than emphasising the departmental perspective. More user-friendly treatment machines[35], including an upright treatment position that literally places the patient and professional eye to eye[36] could also transform some patients' experience.

All the preceding propositions could be collapsed into a meta theme of "Divides". Therefore, I suggest it is crucial to examine how mediating divides might improve everyone's experience of radiotherapy. The current data demonstrate that both authors show mutual interest in forming positive staff-patient relationships. Leotin recommends a focus on radiographers' wellbeing (through stress-management services) as a prerequisite for good patient experience. Both authors recognise that stressed staff are unlikely to provide empathetic human-centred care to stressed patients. The precise and repetitive nature of treatment is perceived as a potential barrier to human connection that could harm what could/should be a mutually supportive relationship:

"Efficiency married with humanity would produce better outcomes for both cancer patients and radiation oncology employees (the strain was visible on both sides)." SL

While making it plain that treatment left her feeling desolate, Diski ponders on the direction of this relationship: *"Perhaps though it was my mood that affected them."* JD p.128

Multiple strands of evidence link staff experience, patient experience and outcome[4,7, 37-39]. A proposed mechanism is that a positive staff-patient relationship improves the staff experience, which consequently reinforces improved patient experience through enhanced staff attitudes or workplace culture. For example, receiving reports of a patient's positive experience may be important to boost staff motivation and morale[17]. If staff experience and patient experience do form positive feedback loops, then the corollary is that divisions are likely to be particularly harmful to the experience of both sides and mediating division will be mutually rewarding.

Limitations

Data selection is a key decision in documentary analysis. Although not required by the method, a systematic approach was used here to identify detailed and authoritative narratives of the patient experience of undergoing radiotherapy. The eligibility criteria meant that only two sources were included. This is valid as it enables an in-depth analysis of experience, however, the inclusion of websites and social media sources would have been likely to provide valuable insights into patient experience. The data here is drawn from two female authors from the global north, who might be unrepresentative of cancer patients in multiple ways. However, the similarity of their experience is

remarkable, despite disparate contexts. Finally, explanatory interpretations are grounded in the data but informed by personal reflection over years.

Conclusions

Patient stories are key patient experience data. Their examination can help radiotherapy services understand the root meanings of treatment from the patient's perspective. They represent powerful data/tools to support meaningful change to services.

Good patient experience of radiotherapy depends on human connection. Divisive phenomena that threaten staff-patient connection include a dehumanising focus on the machine over the person and inadequate consideration of what the machines we use mean from the patient position. The nature of institutions is to tend towards enforcing ritualised roles that deny personhood, which may be further reduced by a heightened human consciousness of death in the radiation oncology setting. The flipside is that establishing a human connection between patient and staff is likely to be mutually rewarding.

Use this article for CPD

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- Reflect on your own practice to consider whether thoughts or behaviours could create a divide between you and patients.
- Identify new developments in your trust that may benefit from seeing from the patient perspective.
- Consider whether reports of a patient's positive experience are disseminated to staff.

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