

## PARTIAL TRUTH TELLING IN THE INTRODUCTION OF NEW HEALTH TECHNOLOGIES: ETHICAL OBLIGATIONS AND EXPERIMENTAL SUBJECTS

### ABSTRACT

**Background** X-ray volumetric imaging (XVI), the focus of a number of fund raising campaigns in the mid 2000's, was introduced accompanied by a fanfare of newness and discourses of 'hope', 'inspiring clinical confidence' and 'accuracy'. The XVI, an imaging technology used in the delivery of Radiotherapy treatment, was incorporated into strategic planning priorities across the UK based on a rationale of self-evidence. During this time the way in which the new system was discussed with patients was variable.

**Research Objectives** The purpose of this study was to uncover how experimental practices were embedded and enacted during the use of a new technological system, specifically relating to how patients were enrolled during introductory phases of technology adoption.

**Research design and context** Drawing on ethnographic work and interviews with staff members in one hospital, the study examines staff discussions prior to the introduction of the XVI technology. It considers how staff views were at odds with practices that occurred once the system was in place during the 'experimental' stage of use with the XVI.

**Ethical Considerations** Approval was obtained from Local NHS Research Ethics Committee and NHS Main Research Ethics Committee (REC 07/Q1308/16) for the interview and ethnographic stages respectively. All names have been changed and participants signed a consent form.

**Findings** Staff reported a lack of evidence, absence of proof and perturbing doubts with the XVI. Both patients' and practitioners' partial understanding about the risks and benefits of the XVI system created incommensurable ideas regarding the use of the system and what the patients' role was during these introductory stages.

**Conclusion** Maintaining partial truth telling renders patients' experiences of treatment at odds with 'experimental' practice. This has wide reaching implications for practice.

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### KEY WORDS

Experimental Practices; Consent; Consent for Research; New Technologies; Truth-Telling.

### BACKGROUND

Withholding truth from patients is a well-debated ethical concern within the medical profession. Tuckett<sup>1</sup> dates the rise of truth telling as a concept to the 1950's following the 1947 Nuremberg trial where it was established that the Hippocratic view of the doctor-patient relationship, centred on beneficence, was insufficient to protect individuals from medical abuses, indicating the need to consent prior to medical procedures. Gillon<sup>2</sup>, in a report to the BMJ, reported that it was Davidson, in 1957, who began the discussion regarding the likelihood of causing harm through prioritising honesty above information relating to a patient's condition. Through these discussions, it was

suggested that withholding the truth could be seen as a mode of evading awkward or unpleasant responsibility.

In literature reviewed by Tuckett <sup>1</sup>, the view that truth telling is essential because it is an intrinsic good, was described along with the argument against truth telling based on the uncertainty principle. These arguments are well covered in the literature and are specifically used in debates over whether a patient would want to or should know the truth relating to diagnosis, usually terminal.<sup>3-5</sup> The main arguments for deception or withholding information from patients are:

- A doctor may add to a patient's distress by telling them distressing news, thus adding to a patient's problems;
- That the truth cannot be communicated because a doctor is rarely, or never, in a position to know the truth or because a patient would rarely, if ever, be in a position to understand the truth;
- That patients do not wish to be told the truth.<sup>2</sup>

Pergert and Lutzen <sup>6</sup> have discussed the relationship of hope and truth telling (again in the context of the diagnosis with severely sick or end of life care). The authors assert that "*healthcare staff protect themselves and others by balancing truth-telling with the aim of preserving hope.*" However, when the truth is uncertainty, this balancing act is not specifically about preserving hope for the patient, rather it may be considered more a balancing of hope that practice can continue undisrupted. Balancing disclosure can thus be considered partial truth telling.

Yet, 'truth' is a culturally constructed artefact. It is not a static object awaiting neutral discovery or delivery by a doctor to a patient.<sup>7</sup> Pergert and Lutzen <sup>6</sup> define truth, in the context of truth telling, as:

*...the subjective truth; that is, what healthcare staff, out of their qualified judgement believe to and are convinced to be true.*<sup>6</sup>

If truth is constructed and subjective, it is possible, therefore, to create truth through the manipulation of information. As such, partial truth telling is a process of informational manipulation, the virtue of which, should be considered based on a practitioner's special moral duties towards their subjects <sup>8</sup>. Partial truth telling affects what a person believes and, as such, informational manipulation and the conditions of understanding are inextricably linked.<sup>9</sup> Truth-telling is, therefore, a dynamic, iterative, and interactive process that takes place between practitioner and patient, sharing many provisional truths in view of a common therapeutic goal. It is related to the doctrine of informed consent,<sup>7</sup> in that it relates to the ability of an individual to be in a position to give 'effective' consent and the duty of disclosure.<sup>9</sup> Effective decision making relies upon the practitioner's duty to disclose facts necessary for 'intelligent' consent.

One problem, of many problems, related to situated practices of truth telling occurs when there is uncertainty over practice, where risks are not 'facts', rather they are 'perturbing doubts'. Telling the truth on uncertain territory can lead to a lack of confidence in practice or the need for overburdening of patients (and practitioners) with details, likelihoods, outcomes, alternatives and also speculation.

Surbone <sup>7</sup> states that one particular difficulty with telling the truth within an oncology context is, “*avoiding therapeutic misconceptions in early-phase clinical trials*” <sup>7</sup>, indeed Lignou and Edwards <sup>8</sup> describe how:

*...intentionally manipulating information can protect and secure a subject’s rights and at the same time benefit society. Moreover, we claim that manipulation of information may also affect a person’s desires to take part in a research without modifying or altering their beliefs and thus that a definition of manipulation of information broader than that found in the literature should be adopted.*<sup>8</sup>

One expects, however, that in a research context, a patient is aware of the context of uncertainty, the circumstance of experimentation. Early phase clinical trials have a formality associated with them – a rhetoric of hope but also a rhetoric of consent, eligibility and structure dictated by the Declaration of Helsinki <sup>10</sup> and Good Clinical Practice guidelines.<sup>11</sup> In these contexts, truth telling is considered a universal principle or virtue – indeed, accepting doubt and uncertainty is often presented as the very basis of altruism in research – doing something unknown for true benefit of others.<sup>12, 13</sup>

In this paper I aim to look at truth telling in experimental practices. For the purposes of the present paper, I am defining experimental practices as *a practice under study or evaluation* and an experimental subject as *a person under study or evaluation*. I use these terms over ‘research practice’ or ‘research subject’ as the categorisation of a practice as research initiates governance frameworks for regulation and safeguarding. I aim to consider how partial truth telling in such practices raises empirical ethical issues for practitioners, patients and researchers alike. I want to move away from truth telling and its associations with delivering diagnosis or prognosis and look at a much more applied, situated and empirical example of telling the truth to patients.

Empirical ethics focuses on the ‘goods’ that carers and patients strive for, the values and norms they inexplicitly or explicitly shape and the ‘bads’ they want to avoid.<sup>14</sup> In working through this empirical case study and exploring the practices as they took place, I aim to reveal embedded values and ideals as they manifest in practice.

## RESEARCH AIM AND OBJECTIVES

Through this case study, I aimed to look at situated ethics, ethical dilemmas that occur in practice, highlighting how contexts of uncertainty and accountability shape responsibilities in experimental practice. The questions I sought to answer were: how do uncertain practices shape truth telling and disclosure, and what is the relationship between uncertainty and responsibility?

## RESEARCH DESIGN

To answer these questions I work through the case of X-Ray Volumetric Imaging (XVI). The present paper draws on two research projects at the Sieverts Hospital over a period of three years. Based in the United Kingdom, the Sieverts Hospital was installing its first XVI system in 2007. The first research project, prior to the XVI installation, involved interviews with staff members conducted shortly after the decision had been made to begin a fundraising campaign for the system. The

second was an ethnographic, mostly observational, study including observations of the installation of the system and what was being done by clinical and non-clinical staff working with it.

For the interviews, all staff in the department (52) were invited to take part in an interview and 14 participants were selected from those returning an opt-in slip in order to achieve a cross-sectional sample i.e. in order to ensure all grades and levels of experience of participant were represented. The sampling method was, therefore, considered to be purposive.

In the second study, the ethnographic approach focussed on the mundane practices around installing and working with the XVI technology, revealing the interplay between machine and human. In 'following the thing', a name given to the process developed by Marcus,<sup>15</sup> the material object of the XVI was traced through several different contexts. Therefore, alongside the observations of what was being done by clinical and non-clinical staff working with the machine, I attended staff meetings and training sessions, I joined the practitioners in coffee breaks and for lunch, I conducted presentations of my research for participants and held group discussions with those I had observed. In addition I examined documents such as training manuals, protocols, patient information leaflets, newsletters, local press and minutes of meetings in order to explore the way that these materials shape, and are shaped by, the technologies they are associated with. I spent portions of my fieldwork observing the machine when no-one was 'doing' anything with it, learning how it became part of the establishment through action and non-action. Physically observing the XVI revealed only a small aspect of the network; following paperwork in the planning department where future treatments were being calculated or discussing doctor-patient consent procedures allowed a deeper exploration.

Throughout the fieldwork observations I took detailed notes, including sketches, which were later transcribed in full. Analysis of these transcripts, alongside other sources of relevant fieldwork material, entailed an iterative reading and coding to identify conceptual themes of interest.

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## ETHICAL CONSIDERATIONS

Ethical approval was obtained from the Local NHS Research Ethics Committee to conduct initial, pre-installation interviews at the Sieverts Hospital. Approval was then obtained from the NHS Main Research Ethics Committee (REC 07/Q1308/16) for the ethnographic stages of the project (which took place on two sites, although it is just the Sieverts Hospital presented here). Approval was sought and granted from local hospital trust Research and Development committees. Written consent was obtained from all staff participants for the interviews and from staff who were observed as part of the machine installation and early use. The names of staff members and the hospitals have been changed to preserve anonymity.

## EMPIRICAL SECTIONS

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### *X-RAY VOLUMETRIC IMAGING*

X-Ray Volumetric Imaging (XVI) is a type of imaging introduced into radiotherapy treatments in order to improve the positioning of radiation beams during targeted cancer treatment. In the context of the system described in this paper, the XVI, it involves adapting a radiotherapy treatment machine,

or linac, so that the machine can take a Computed Tomography (CT) scan (or Cone Beam, CBCT, scan) of a patient prior to delivering a daily dose of radiotherapy. The CT scan images are then assessed prior to the patient receiving their treatment to ensure that the treatment radiation will be delivered to the correct location within the patient body, avoiding unnecessary treatment of healthy tissue.

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### KNOWING ABOUT RISKS

In interviews with staff at the Sieverts Hospital held prior to the introduction of the XVI technology, practitioners at the centre of the technological change discussed a lack of evidence, absence of proof, a lack of compatibility with existing systems in use, the politics of decision making processes and perturbing doubts<sup>16</sup> Fuelled by a lack of evidence for the procedure (and an introduction based on axiomatic certainty),<sup>17-19</sup> this sceptical perspective was maintained by some during the installation phases of the equipment. This is evidenced by the following conversation between Jo and Samantha (two senior members of staff in the department):

*Jo is asking Samantha about how they are going to use the XVI once it has been installed. Sam answers but says that they are thinking in a very theoretical way "because we don't know." ... Jo says "Then in 20 years we'll be treating all the secondaries [secondary cancers] from the kV imaging!" Sam says she'll have retired by then and Jo jokes about how the secondary cancers will be Sam's "parting shot".*

From field notes, 8<sup>th</sup> October, 2008, p.2

During the fieldwork over the course of the installation phases, however, these discussions appeared to recede. I infrequently, if ever, heard practitioners discuss radiation dose from the CBCT scans once they were being used on patients. The extent to which scanning procedures are discussed with patients is limited, if discussed at all, as the practice of taking the scans, and hence the associated radiation doses, have been 'normalized' into the procedures for verifying treatment position, showing the limitations of the informed consent procedures. The patients are consented for radiotherapy treatment and the risks of that are conveyed, however, any additional doses, or nested procedures, a patient may be exposed to are not considered beyond that initial consent procedure. Yet the conversation between the two radiographers, Jo and Sam, suggests that things should be otherwise. The unknown or speculative risks involved in the procedure, discussed in interviews and later in these informal conversations, are not at any stage discussed with the patients.

It may be the case that those faced with the prospect of treatment might choose the benefit of increased life expectancy and accept the risk of a secondary malignancy, a risk suggested by Jo and Sam. However, as this is not brought into the discussion with patients they are denied the opportunity to address this choice.

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### EXPERIMENTAL SUBJECTS

Throughout observations at the Sieverts Hospital it became apparent that the introduction of Cone Beam CT (CBCT) scanning into the treatment of patients with prostate cancer was experimental, with no real consistency or evidence base for the practice. I use the term 'experimental' here to denote the untried or untested way in which patients were exposed to the new procedures

with little or no knowledge of outcomes (on both the part of the patients and the practitioners), rather than an alternative reading which would suggest patients were part of a controlled experiment or 'trial' to improve treatment outcomes. Therefore, through the following account I highlight how patients were performed as experimental subjects during the introductory stages of the X-ray Volumetric Imaging (XVI). Through the following detailed description of the experimental patient, including how this role is later derided, I highlight how these practices, whilst being accounted for, create incommensurable ideas regarding the use of the system.

When the Sieverts Hospital began to use the XVI equipment on patients, this was described to me by one of the radiographers, Louise, as having "*not started using it clinically yet*". Despite this 'non-clinical' use, ten patients were having weekly CBCT scans and weekly, additional, Electronic Portal Images (EPI) taken. These EPI images are the traditional images used to verify a patient's position which, at the Sieverts Hospital, involves additional radiation, as an area larger than the treatment field is used to acquire the images. On this occasion, the rationale for taking these additional EPI images at the same time as CBCT scans was to determine if the displacement of treatment position, acquired from the CBCT, was the same as the displacement observed using the traditional system. This kind of testing appeared to be reiterating the mechanical quality assurance tests, performed on the equipment daily without exposing a 'real' patient, used to confirm that the CBCT images and the EPI images are congruent.

Frequently staff in the department told me that they were not going to look at these additional images; that they weren't being "*actioned*". Therefore, despite the images being taken prior to the radiotherapy treatment being given, no-one was examining them until all the images for each patient had been taken, by which time the patients could have finished their course of 30 plus treatments over a six or seven week period. This was contrary to the purported benefits of using the system where daily CBCT scans are taken and reviewed prior to patients' treatment enabling corrections to be made. Due to the circumstances of patients receiving additional radiation doses due to these additional images being taken, this was discussed with radiographers in the department.

*We acquired CBCTs and EPIs on ten prostate patients. The results were analysed in conjunction with Seb (physicist) and then presented to the clinicians at a protocol review meeting. The results were basically used to confirm the XVI bone match results were comparable to ... EPI's which provided a level of confidence in a new system and also, provided radiographers with experience using the XVI system.*

Personal Communication with Louise, 11<sup>th</sup> April, 2011

This 'trial', co-ordinated by Louise and analysed with Seb, one of the department's medical physicists, was presented to the clinical oncologists responsible for patients with prostate cancer, once the results had been obtained.

Louise describes the 'trial' as providing a level of confidence in the new system and providing experience for practitioners in using it. However, it was not described to the patients in this way. This can be seen in the patient discourse used when discussing their treatment, as described below.

The installation of the XVI equipment at the Sieverts Hospital was publicised by the Charity responsible for raising funds for its purchase. During the launch of the XVI, in a local newspaper, a

patient who was told he would be receiving image guided radiotherapy, the CBCT scans, was interviewed. The text from the newspaper read:

*Mr George, 77, of [town] near [district] is one of the first patients to be treated. Mr George is being treated for prostate cancer. He said: "My doctor told me that surgery was too dangerous at my age, so I have just started this treatment. It is brilliant to know that I am one of the first patients to be having the newest cancer fighting treatment and that the radiation will just beat the cancer without damaging healthy cells."*

Taken (and adapted) from the local newspaper April 3rd, 2009.<sup>1</sup>

In the newspaper clip Mr George is put into the spotlight by the Charity or the department management who collaboratively organised the press event, and, proclaims his thanks and wonder relating to being one of the first patients to receive this 'newest' treatment. In the act of wholeheartedly supporting the new technology, which he believes to be giving him targeted treatment 'just' to the cancer, he endorses that treatment.

However, Mr George is one of the ten patients in the trial of the XVI system who is not receiving any alteration to his treatment. As such, there is an obvious discrepancy between the rhetoric of 'not being clinical' indicated by Louise, and "*having the newest cancer fighting treatment*" as understood by Mr. George.

Later into Mr George's treatment, this contradiction manifests once more. Mr. George and Mr. Fox, both receiving radiotherapy treatment for prostate cancer at the Sieverts Hospital, were routinely having their treatment on the XVI adapted linear accelerator, LA6. The two men were both in the 'trial' of the XVI system. One day, when LA6 had broken down, it transpired that these two patients chose **not** to have their treatment on a machine that did not have an XVI attachment, LA3. This decision was informed by their belief that they were being treated with the 'newest' technology.

When I was being told about the patients choosing to have their treatment on LA6 rather than LA3 I asked the radiographers working on the XVI if the patients were aware the scans were not being examined, as the newspaper report suggested Mr. George believed otherwise.

*She [Nikki, a junior radiographer] says most of the patients, like this one (on the bed at the moment, not having a scan today) are "just like yeah whatever, do what you want" but there are two which "don't stop going on about it" [Mr. George, quoted above, was one of these patients]. Nikki says they sit in the waiting room telling everyone they are having the best treatment. She says that last week LA6 broke and they were on LA3 [without the XVI capabilities]...but they knew they would get LA6 back by 5:30. Nikki says that these two patients said they would wait until 5:30 so they could get the best treatment. I ask Nikki if the patients know that no one is actually looking at the scans and she says "yeah, they know everything".*

Monday 11<sup>th</sup> May 2009, p.4

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<sup>1</sup> The exact text of this quotation has been changed to protect the identity of the patient and the hospital. The meaning remains.

The reluctance of these two patients to be treated on the older machine due to them receiving “the best treatment” implied to me that they could not know everything. Not only were these patients receiving an extra dose of radiation from the additional EPI and CBCT scans, they were not getting any of the benefits which the XVI had promised. One of the main advantages put forward by the charity appeal was that XVI would provide a more accurate treatment through improving the department’s image guided radiotherapy (IGRT) techniques. One of the appeal pamphlets states “*IGRT allows radiotherapy staff to take CT quality scans during each treatment session, identify movement and changes and alter treatment automatically to accommodate for them.*” This is what we can assume Mr. George thinks he is receiving when he speaks of his treatment just targeting the cancer ‘*without harming healthy cells*’. In practice, however, the treatment is not significantly different to that being received by patients who are not being scanned with the XVI technology.

The framing of the 'trial' as a way of ensuring staff are familiar with the machine, rather than a research trial, positions the patients as experimental subjects, rather than research subjects. Had this framing of been otherwise, and the patients were 'research subjects' then the Declaration of Helsinki would apply<sup>20</sup>. This framing raises important questions regarding the validity of consent. The patients consented to the treatment procedure (although there is no specific consent for nested procedures within the radiotherapy treatment) yet the purpose of the experimental scans was not discussed with them, an example of partial truth telling. Another radiographer in that department told me she thought that this trial was ‘wrong’; yet this conversation took place well after the event and was never publically voiced. There were risks involved in additional scans (as the conversation between Jo and Sam demonstrates) however, in routine practice, it is assumed that this risk outweighs the benefits of the advances in treatment. Yet, if there is no advancement of treatment for these patients, should they not have been informed about the risks? The governance requirements of experimental practice and research practice are different and, as such, create differing levels of explanation for the patients. Furthermore, the direct patient benefit of experimental (staff training) practice versus ‘new’ treatment also differs. The scans taken during the experimental practice were no longer a nested treatment procedure for these patients, rather a research project that ought to have been consented independently of the treatment.

## DISCUSSION

This paper is situated in an in-between space: the space between patient and practitioner and the temporal space between machine installation and routine practice. Through taking a praxiographic approach to ethics and truth telling – that is one that studies things and people in their relations<sup>14</sup> - it is possible to problematize ‘truth telling’ in these contexts and consider how patients’ experiences of ‘new’ treatment can be at odds with ‘experimental’ practices.

This illustration of situated ethics highlights the way in which practitioners inhabit the ‘*technological frontier*’ of the ‘risk society.’<sup>21</sup> In the process of stabilizing a technology into practice, the uncertainty and diversity of possible futures becomes forgotten, or ‘black boxed’, as demonstrated by the absence of talk about risk or dose, once CBCT scanning was fixed in treatment routines. Whether the practitioners accept the risks associated with these technologies or they choose to overlook them is unclear. However, what results is an absence of truth telling within practices of acquiescence to the purported value of the installation.

The case of introducing image guided radiotherapy technologies into practice could be considered a site where potential uses of the technology have taken precedence over knowledge about their associated risks. This decadent technology<sup>22</sup> was promoted as the latest and best system for improving the accuracy of radiotherapy treatment. Despite the lack of knowledge about the increased dose from additional cone beam CT scans, the risk was classified as inevitable or, at least, someone else's responsibility. Doubts were neither formalised nor well researched and, as such, there were no 'facts' on risk to share with patients.

When it comes to applying the XVI system into practice, it appears that those actors developing techniques for usage, advancing technological practice, stop thinking in terms of risk and prioritize application. When practice takes over, the act of using the systems takes precedence. Issues such as protocol development, accidental injury and case load management are considered relevant and hence become associated with the technology, leaving those initial risky decisions considered closed and hence not up for discussion with the patient.

We see from the presentation of this ethnographic material that the actions of the patients were at odds with the 'experimental' nature of the new system. In positively connecting with the trial and their treatment with the XVI, the patients provided practitioners with an opportunity to reaffirm their accountability. The choice of Mr George and Mr Fox to wait for their treatment involving the CBCT scan, validated the actions of practitioners in performing the scan through displaying their choice to receive the 'newest' treatment.

In this sense, as Charis Cussins suggests, the patients maintain influence on their healthcare treatments by making decisions about them, resulting in patients being neither a victim nor helpless in this process.<sup>23</sup> Contrary to Cussins' work on fertility treatment however, the patients in the present research, those invoking the right to be treated on what they perceive as superior machinery, are making decisions situated in the context of 'life saving treatment' and, as such, the context of different life goals than those of fertility treatment. Furthermore, these decisions are founded on incomplete knowledge.

It seemed absurd to Nikki that the patients would wait to have their treatment on the LA6 machine but, for Mr. George, it could be interpreted as a means through which he can maintain control of his treatment **and** his cancer. Through applying his partial and constructed knowledge of the benefits of the 'new' treatment, he is able to make a decision about his treatment. The performances of the patient – those who, according to Nikki, are passive in letting the radiographers do what they want or those who actively participate in the decisions about their treatment – are influenced by their interpretation of the (partial) information regarding the CBCT scans. Their capacity for action was therefore located within the confines of the knowledge they have received from the radiographers and various other sources, for example the charity funding the machine installation. Patient actions are therefore shaped by the level of understanding they are enabled to obtain and practitioners directed the actions of the patients through maintaining these partial levels of understanding. Such partial truth telling created order and justification for practitioners' own practices. By not correcting what aspects of 'new' treatment they were getting, practitioners ensured the patients remained engaged whilst being protected from any suggestion that what they are doing was questionable. The radiographers also make an implicit deferral to the authority of the patient's consultant as, under the regulatory framework of exposing patients to radiation,<sup>24</sup> responsibility for obtaining informed

consent for the radiotherapy procedure and responsibility for the patient's exposure, ultimately lies with the consultant.

The patients had no formal sources of information regarding this trial. They consented for radiotherapy treatment, the risks of which were explained by the consultant, and they were told they were being treated on the machine with the new 'life saving' technology. Through the process of partial truth telling relating to the potential benefits of the system, Mr. George was transformed into a patient who wanted to be treated on that system. In not receiving information about the nature of the scans, he maintained this position (although that is not necessarily to say he would decide not to receive the scans should he be informed differently). Following Lignou and Edwards<sup>8</sup> *"the fact that a researcher has manipulated a potential subject's decision does not in and of itself make it morally problematic"*. However, as they elaborate, what is of moral concern is what the researcher intends to achieve by manipulating the information presented to a patient. Whilst there may be no legal issues with the validity of the consent for radiotherapy, there is a moral question regarding the validity of consent for nested procedures, for example the image guided radiotherapy process.

In the case study I have presented here, partial truth telling to patients created multiple patient positions, exemplified by both those who let the radiographers 'do what they want' and those who 'don't stop going on about it', and thus also facilitated support for the use of the XVI. This legitimated the actions of the radiographers involved in the trial of the XVI with the ten patients. Nikki says, *"Yeah, they know everything"*, suggesting that the patients were given **all** possible information and therefore made an informed decision, justifying the radiographers' practices in this instance.

Through the multiple actions from patients, radiographers and the XVI, the role of the XVI as 'innovative' and 'best' was **accounted** for. However, in the case of these patients, there was no therapeutic benefit and hence the involvement of the charity, and associated rhetoric, heightened the therapeutic potential of the system being introduced. It may be that these patients were fully informed about the trial of the XVI technology however the statement in the newspaper and their actions regarding waiting for treatment on the 'newest' machine suggest otherwise. The case study presents a case where 'informed consent' was invalid as, in essence, the subjects have been deceived. The fact that the patients appear to fully agree to the study does not actually grant the practitioners authority to perform the intervention.

Surbone<sup>7</sup> argues that a preoccupation with autonomy and partnership leads to the application of rules of reciprocity that do not capture the essence of the patient-doctor partnership: a dynamic, asymmetrical relation with unequal knowledge and power. The patient looks to the practitioner, they invest in medical authority as a result of the consent to treatment and all that it involves. In order to deliver the radiotherapy in line with the CBCT imaging protocols, the practitioner accepts that someone, if not them, has evaluated the risk and it is acceptable.

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#### AUTHOR'S REFLECTION

Uncovering the circumstances of the experimental practice and the partial understanding of the patients placed me in a very difficult situation. It was not plausible to consider discussing this with

the patients involved and therefore all I could do was, to the best of my ability, raise this with other practitioners in the department. Asking questions such as, “do the patients know?” “what do you think about...?” As I have indicated in the main text, my position was either refuted, “They know everything”, or it was confirmed but only in private.

## CONCLUSION

In this paper I have presented the case of experimental subjects during the introduction of X-ray Volumetric Imaging (XVI) in radiotherapy treatment practices. The aim of the paper was to look at situated ethics to highlight how contexts of uncertainty and accountability shape responsibilities in experimental practice to answer the questions: how do uncertain practices shape truth telling and disclosure, and what is the relationship between uncertainty and responsibility?

As the case demonstrates, truth telling in experimental practices is not a reiteration of well-established debates concerning informed consent for treatment. Rather it is an example of practitioners legitimizing action with new technological systems through managing their uncertainty. Routinely, there would be no informed consent for the procedure of localisation or imaging nested within the wider context of radiotherapy treatment. However, in the experimental practice described, the ethical obligation of disclosure was marginalised. The case shows how the dynamic and interactive process of truth telling was destabilised by uncertainty. The practitioners removed themselves from taking responsibility for telling the truth to patients in order to work with, or ‘park’, any uncertainty relating to their duties and, therefore, continue to practice.

The patients’ partial understanding of the practices they were being exposed to and the practitioners’ partial understanding relating to the risks of the system, created incommensurable ideas regarding the use of the system. By maintaining partial truth telling and not clarifying exactly what the degree of knowledge the patient had about the system, for example ‘the patients know what is happening’, practitioners worked to account for their actions and formed boundaries around their actions in order for those actions to make sense to them. As such, patients’ experiences of ‘new’ treatment can be considered at odds with ‘experimental’ practice. This has wide reaching implications for practice. By making uncertainty visible and present in discussions with patients a more open and responsible practice would surely follow. On-going, forward and backward looking reflection would shape services in a way which would be accountable to those who will be affected by outcomes.

An inherent weakness with the project was the lack of patient voice in the data collection. Further research should aim to include the patient whilst remaining sensitive to how uncertainty is discussed and hence revealed.

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