

Patient involvement and expectations during CT scans. Tinkering to involve patients and offer care in radiographic practice



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ABSTRACT

Introduction: This study investigated how patients expected and experienced to be put first and cared for in diagnostic imaging settings and how putting the patient first was operationalized in practice.

Methods: A qualitative field study was conducted in two Danish hospitals to investigate patients' expectations and experiences of care and involvement during CT examinations.

Data collection methods included semi-structured interviews and participant observations of five examination cases. Three Computed Tomography (CT) guided lung biopsy intervention studies and two conventional CT studies of the chest of patients being investigated for lung cancer in Fast Track Cancer Referral Programs (FTCRP) were included.

Results: Patients reported low expectations of receiving care and being involved during examinations. Perceptions of receiving care predominantly consisted of being received in a kind, personalized manner. Expectations of involvement in the procedure were reported in terms of readiness to do as they were told, complying with requests put to each patient.

Concepts of care and involvement were challenged in their formal meanings and found to be entangled in complex interactions within sociotechnical boundaries.

Conclusion: Patient's expectations of receiving care and being involved in the diagnostic imaging procedures, were expressed in noncommittal terms, and were overshadowed by patients' focus on getting through the examination, in order to get an answer to their tentative diagnose. The concepts of care and patient involvement were negotiated and reconceptualized within the sociotechnical framework of the diagnostic imaging situation of the individual patient. The concept of "tinkering" is suggested as a means of understanding how patientcare is performed during diagnostic imaging procedures.

Implications for practice: Issues were identified that may help professionals to put "the patient first", thus, improving patient centered care.

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Introduction


This paper concerns the relations between humans and technology in a complex health profession; radiography. In our view, this profession can be characterized by two dimensions; a human science dimension and a techno-science dimension.¹ The human science dimension is configured through intricate human relations and interactions in dire health situations. It involves

aspects of care, communication, and ethics among others. The techno-science dimension is configured around the laws of physics and involves high technology, ionizing radiation, magnetic fields, ultrasound, and complex procedures to produce anatomical images. In radiographic practice, the two dimensions ideally meet in a beneficial balance in both patient care and the objective outcome.

The radiographer is committed to both dimensions. However, it is possible to engage in the practice of radiography prioritizing one dimension over the other, emphasizing the relative objectives of one dimension. Hence, the radiographer either predominantly strives to achieve optimal image quality, following strictly technical

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criteria, or mainly attempts to provide the best possible care, complying with patients’ preferences.¹

An inadequate balance between the two dimensions, with an emphasis on the complex technological procedures, may have negative consequences for the patients. It can influence their experience with radiological procedures in undesired ways, like feeling abused or objectified.^{2–5}

This study investigated the balance between the two dimensions with a particular focus on patients’ perspectives of being involved and cared for during diagnostic imaging procedures. More specifically, the article investigates; 1) how the human-centered and the techno-science dimensions are balanced in concrete Computed Tomography (CT) scanning situations, and 2) how the two dimensions create mutual friction during examinations with patients undergoing lung cancer investigation referred through Fast Track Cancer Referral Programs (FTCRP). In this study, we interviewed patients about their expectations of being involved and receiving care in technologically governed settings, and we studied how care was performed in everyday radiographic practices.

Patient involvement is included as one out of eight prioritized goals in The National Goals for Healthcare in Denmark, as a part of the National Quality Program since 2016.⁶ Thus, it is associated with contributing to enhanced quality in healthcare, improved treatment outcomes and patient experience of care.^{7,8} It is vaguely described throughout the literature, what precise elements are included in patient involvement, and how they relate to the patients’ experiences of care.^{7,9–11} Many different terms are used to describe the involvement phenomenon, such as ‘patient engagement’, ‘patient participation’, ‘patient centeredness’, ‘shared or joint decision making’ and ‘empowerment’. In addition, there is a distinction regarding the term describing the person(s) involved, including patients, users or citizens, which draw an unclear picture of what patient involvement means.

In this study we will use our findings from interviews and observations to make the patients’ voices heard intending to improve the quality of patient care and involvement in radiographic practice.

The patients in our study belonged to a specific category investigated for malignant diseases. In the Danish health care system, these patients are grouped into FTCRP. Such programs are specifically designed trajectories containing predefined examinations and procedures intended to be performed within strictly set time limits, reaching from referral, through diagnostics to initial treatment.¹² The examinations included in our study were part of such trajectories. The results of radiological examinations often have a determining character, contributing to decisions concerning which treatment to offer the patient. In case of cancer detection, it may determine whether treatment can be carried out with curative or palliative intent.^{13–15}

The research culture within the profession of radiography is dominated by a quantitative techno-scientific focus. Nevertheless, qualitative research, examining phenomena such as patient experiences, emotions, and relationships, has increasingly been carried out within the field.^{16,17}

The purpose of the study was to explore patients’ experiences and expectations of care in radiography, based on human–technology relations. In so doing, this study contributes to the qualitative research in a Science and Technology Studies (STS) perspective.¹⁸

Ethics

The study followed the guidelines of the Declaration of Helsinki,¹⁹ the General Data Protection Regulation (GDPR)²⁰ and was approved by Aarhus University Journal nr.: 2016-051-000001.

All participants received both written and oral information about the purpose of the study. The information clearly stated that their anonymity was reassured, and their right to withdraw their consent from the study at any time. All participants signed an informed consent.

Materials and method

The research questions had a qualitative approach with a focus on human–technology relations, and how human experiences are transformed through technological mediation.²¹

The study involved five patients (aged 38–78) under investigation for lung cancer (see Table 1).

Two patients underwent conventional diagnostic CT scans of the chest with intra venous (iv.) contrast. Three patients had CT guided lung tumor biopsy interventions performed.

Access to the patients, referred for this specific procedure, was determined by the radiology department. The patients were included according to the referred order over a three-month period. At this point in a FTCRP, patients are usually aware that they potentially have a malignant lesion(s) and the nature of the lesion(s) is to be revealed by the intervention procedure, for targeting treatment.

The researchers were susceptible to the involved patients’ particular vulnerability and possible crisis undergoing cancer diagnostics. Each patient’s cognitive and emotional state was subjectively assessed to avoid recruiting patients, who displayed high levels of emotional stress. We evaluated whether they were able to understand and answer relevantly to the questions asked, and whether they had strong emotional outbursts during the communication.

The three patients undergoing CT guided lung biopsy were approached and selected by an experienced research nurse specialized in respiratory medicine.

The two patients undergoing the diagnostic CT scan were included to increase the total number of cases in the study all having comparable modalities and targeting the same potential pathology. They were included in the referred order during a period of two days and selected by a medical secretary, who contacted the patients by telephone to schedule the FTCRP appointment. All patients were selected based on the professionals’ assessment and following the inclusion criteria. All the patients, who were offered participation in the research project, accepted participation. The patients were given 24 h to reconsider their participation.

A qualitative field study was performed combining semi-structured interviews and participant observation as data collection methods. The five patients provided five cases, each offering in-depth insights into the subjective human centered dimension of the radiographic examination with a focus on the experienced human–technology relations. The aim was to obtain detailed descriptions of relational processes and patient’s first-hand individual narratives of the issues at stake.

A qualitative approach provides deep insights into individual human life conditions and understanding of phenomena by interpreting and investigating nuances in depth.^{22–25}

Table 1
Patient inclusion criteria.

Criterion	Assessment
Age	>18 years
Language	Fluent in Danish
Other	Able to provide a competent informed written consent. Emotionally stable

Inclusion criteria are listed in Table 1.

Table 2
Specifications for data collection.

Patient	Gender	Examination	Interviewed prior examination	Observation: During the examination and in waiting area	Observation: In the hospital ward, during transportation
P1	♀	CT of thorax with iv. contrast	+	+	–
P2	♂	CT of thorax with iv. contrast	+	+	–
P3	♀	CT guided lung biopsy	+	+	+
P4	♀	CT guided lung biopsy	+	+	+
P5	♂	CT guided lung biopsy	+	+	+

An overview of patient gender, type of examination, and data collection is shown in Table 2.

Interviews

Following a semi-structured interview guide, all patients were interviewed by the first author prior to the examination about their expectations of being involved and cared for during the procedure.

The interview questions focused on the patients' expectations prior to the examination, specifically on how they expected to be met, treated, and involved during the procedure.

The face-to-face interviews took place in designated rooms close to the radiology department and lasted between 25 and 30 min each.

Participant observations

Participant observations were carried out by the first author during the entire diagnostic examination and the waiting time spent in the radiology department before and after the examination. The observations mainly focused on how care was performed and received, by observing in detail the actions and interactions between professionals, technology, and patients.

The observations lasted between 30 and 60 min.

Data analysis

The interviews were recorded and transcribed verbatim. The transcriptions were read intensively as a whole, to gain an over-all understanding of what the patients expressed about the phenomenon. The transcriptions were re-read several times applying NVivo12 Mac software to code for themes and concepts of interest that were responsive to the research question and objectives. Consequently, they were analyzed following Kvale and Brinkmann,²⁴ applying a pragmatic approach, guided by the research questions.

The observations were documented and analyzed through transcribed field notes and photographs. The field notes and photographs were coded for themes and concepts following a general conceptual framework derived from STS sources; “the logic of care versus the logic of choice” by Annmarie Mol,²⁶ and post-phenomenology based on Don Ihdes' four types of human–technology relations; embodiment relations, hermeneutic relations, alterity relations and background relations.²¹

Results

The overarching themes identified in both data sets were: patients expectations of receiving care and being involved were low; patients struggled to get through the examinations; patients demonstrated willingness to fight through driven by their focus on the result of the examination. The themes are elaborated and discussed below.

Patients' expectations of being cared for and involved

The patients unanimously expressed low expectancy levels, when asked about their expectations of receiving care during the

examination. They commonly reported that they associated care with being received with a cordial attitude, getting adequate information and guidance through the scanning. The patients reported that they did not imagine that the radiographers would take any specific care-related measures or actions.

Patient P5 described he had no idea how the radiographers should care for him during the examination. He expected the radiographers to be smiling and friendly and he was ready to be received as the next in line, with no claims to special treatment.

P5 “No, I don't know how they should care for me it's their job, it has to be done they have so many [other patients]they have to go through in one day, and I am one of them ... I don't need any special treatment.”

Four out of five patients had issues with pain and/or anxiety, but none of them expected that any measures would be taken by the radiographers to relieve them. Two patients explained they would inform the radiographer of their difficulties prior to the examination to prepare them in case they ended up not being able to go through. However, they both expected to deal with their difficulties mostly by themselves.

Patient P3 explained her expectancies of care as follows:

P3: “I always have to handle things myself... if they come and give me their hand and tell me what I have to do, then I have received care.”

Patient P2 had numerous experiences with the healthcare system and explained that he was used to solving his own issues.

P2 “... yes, I expect them to respond to it at least [notion of his pain and breathing difficulty], whether we find a solution is something else. ... I, myself may come up with the solution to it.”

When asked about their expectations of being involved, most patients said that they did not have sufficient knowledge about the examination procedure to build any expectations on. However, a common expectation shared by all patients was to not be involved, and instead submit to the radiographer's requests and endure whatever pain and discomfort they might experience.

The patients expressed this differently:

P1 “... not beyond lying still and being quiet... well ... and doing as they say.”

P2: “... I just have to endure and lie flat on my back”. ... “you just lie down on the couch and keep quiet through the investigation.”

P4: “I just have to decide to lie down and leave the work to the staff ... because after all, I can't do neither one, nor other.”

The complexity of patient involvement and choice in radiographic practice is illustrated in the case of patient P3.

P3 was a woman with a history of having ovary cancer, and therefore had a wide range of scanning experiences: MRI scans, internal and external ultrasound scans, and PET CT scans. She did not know what kind of scanner she was going into for the CT guided

lung biopsy, but she was very afraid, because she suffered from claustrophobia.

She had experienced a great deal of emotional distress undergoing some earlier scans, but she had, as she phrased it: “fought through them”. On one occasion, the scanning had been aborted because she had a panic attack whilst laying in the gantry.

She had, however, chosen to go through with the CT guided lung biopsy because of “the need to know” if the tumor was malignant and what kind of treatment she would be offered. The “need to know” overruled her fears and other aspects of the examination.

She explained:

“... they can do as much to me as they feel like, but ... I fear that I have to go into the scanner... that I have to lie in there. “... I must get through it! So, I will soldier through and fight when I'm in there! ...I will do so because we must know, we really have to [emphasized].”

Choosing not to go through with the examination, was not an option in the eyes of P3. She was determined and needed to get an answer. Choosing not to go through with the intervention would be the same as giving up on knowing if the tumor was malignant or not, and if so, giving up on the idea of curative intended treatment and submitting to whatever disease trajectory might be in store for her. As a patient, P3 did not choose, but she was in need of care to achieve her goal.

Discussion

We have applied an STS approach as theoretical and analytical framework of our investigation. Besides Postphenomenology, we focused on the work by the Dutch ethnographer and philosopher Annmarie Mol.

In her book *The Logic of Care*,²⁶ she introduces the theoretical and analytical concept: logic of care as contrast to logic of choice. This is to counter ‘cultural blindness’ to the undesired consequences of health care based on individual patients’ own choices. Mol argues that exercising autonomous choices as citizens or customers make sense when you are in control of your body and free to choose a product or service of your liking. When you are not primarily a citizen or customer, but rather a patient, you do not control your diseased body; it is unruly.

Thus, patients are embedded in irregular situations, and they do not choose care. Neither do they choose to have a disease, nor can they deselect it. Conversely, they need care.

Mol states

‘Good care’ is not a matter of offering more choices to each patient. Instead, it is about ‘attuning’ knowledge and technologies to bodies and lives in everyday practices in the ward at hospitals and elsewhere. We cannot just observe and judge the world from the outside. “Instead, we are caught up and participate in it, body and all.” [26, p. 94].

Mol uses the term ‘logic’ to address the rationality in and of a specific practice. That is, what is appropriate or reasonable to do in certain places or situations, and what is not? She argues that caring is not a transaction where something is exchanged, but an interaction where the action goes back and forth in a continuous process. She states that the care process involves a team. The team does not only include the professionals, but also the patients and their bodies and non-human devices, such as drugs and technologies. The tasks involved are shared among the team members in varying ways.

“The care process involves a team (of professionals, machines, medication, bodies, patients and relevant others), and tasks are divided between the members of that team in ever-changing ways” [26, p.21].

According to Mol, central to all things involved in care procedures is that they are somewhat unpredictable. Living bodies and technologies are erratic, and do not always behave as promised or prescribed. Sometimes they do - more or less - what is expected, and sometimes, they do something not bargained for. Caring is therefore an inventive and adaptive process, where changes are continuously made to make things work: everything has to be adapted to everything involved, one way or the other. She uses the concepts of tinkering and doctoring to signify this adaptation task of combining everything with everything.²⁶ Tinkering is hence the continuous manipulation of things (patients, bodies, technologies, etc.), in the attempt to make them work and do it in concert. Tinkering is a concept related to cheating and fiddling, but Mol uses the term positively to describe the ongoing attempts to mend or improve, that is, to get things done in situations that cannot be fully controlled (see also²⁷).

Mol conceives care in the following way

“As control is illusionary, as all the elements involved (bodies, technologies, food, colleagues, what have you) are capricious, the task is that of attuning everything to everything else, one way or another. What to fiddle with and what to keep fixed, is rarely obvious. What you try to do, may not work out. Try something else. Keep on tinkering. Doctoring. Caring.” [28, p. 1757].

Following this suggestion, care in radiographic practice cannot only be held to include human relations. The technological devices that inevitably are part of practice, are also team players in a care process. Thus, patients, their bodies, radiographers, radiologists, scanners, monitors, protocols, contrast agents all take part and share tasks among themselves in varying ways. Therefore, to make care as good as possible, is to a high degree a matter of tinkering.

Tinkering and caring in radiographic practice

Examples of tinkering in radiographic practice, where things cannot be fully controlled, can in fact be found everywhere, since all examination situations involve some degree of tinkering. Patients seldom fit into standard protocols and procedures, and not all protocols and procedures fit the patients they meet. No two patients are identical. That also goes for their anatomy, which entails significant individual variations (heavy or light, tall or short, etc.), although their bodies consist of the same organ elements. Exposure parameters are adjusted to the individual because the radiation is increasingly attenuated and scattered with increasing body size, calling for various degrees of tinkering if a good result is to be reached. Arranging and positioning patients’ bodies for optimal insight possibilities, adjusting predefined protocol parameters to individual body habitus and postprocessing images to enhance quality, are some examples of such tinkering.

Field notes from observation of P3 illustrated this.

When P3 arrived at the radiology department, she was agitated. She told the radiographer about her claustrophobia and fear of getting into the scanner. However, she insisted on her will to go through it anyway and ensured him that she would fight to get through it. Responding to the patient's distress, the radiographer changed the usual examination procedure. Instead of disclosing information and answering questions while the patient was in bed, the radiographer

asked P3 to get out of the bed, and then he walked her over to the scanner for her to see it from an upright position.

The radiographer and P3 stood together while he told her objective facts about the scanner, such as length, height, gantry diameter and the estimated time of the examination. He pointed out what would be visible from the inside of the scanner when one was laying down. He pointed out the decorations on the ceiling and discussed how much of her body would be inside the “tube”. Integrated in their conversation he gave detailed information about each step of the examination and how it would proceed.

Subsequently, he offered P3 a test ride in the scanner, prior to the examination, which she agreed to. P3 was positioned and moved headfirst into the scanner, approximately to the same couch position as for the intervention. The radiographer tested different relevant couch positions while explaining, what he was doing and frequently asking the patient what it was like. P3 answered approvingly to technological tinkering and when the test ride was over, the patient expressed, she was ready for the real examination which she completed successful, without emotional distress or complications.

In this observation the patient was involved in the examination in a caring manner not as a person who had to make choices but as a person who was listened to.

Bias

The participating radiographers were informed about the aim of the study, which may have had an influence on their conduct towards the patients during the procedure. Communication between patients and radiographers may have been affected by the research situation, for instance a changed attitude by the participants. However, we see this bias somehow countered by the strict choreography of the examinations.²⁹

The first author, who performed the observations and interviews, was a trained radiographer, who was acquainted with the staff and examination procedures prior to the fieldwork. This influenced the results: On the one hand, the researchers' knowledge of the examination procedures and staff enabled deeper insights into the field.²³ On the other hand, some participants may have adjusted their behavior, i.e. to appear more caring. We think this bias was weakened by the researcher's appearance in hospital uniform, thereby blending in as a colleague. Studying one's own culture may give the advantage of capturing social processes and understanding underlying motives for particular events and choices.

Experienced staff excluded patients displaying high levels of emotional stress. This may have affected the level of care needed and provided during the examinations.

Conclusion

The patient's expectations of receiving care and being involved in the diagnostic imaging procedures, was expressed in non-committal terms. The expectations were overshadowed by the patients' focus on getting through the examination, striving to get an answer to their tentative diagnose.

The concepts of care and patient involvement were negotiated and reconceptualized within the sociotechnical framework of the diagnostic imaging situation of the individual patient. When patients were asked about their expectations of receiving care during the examinations, they all had low expectations. The patients also reported that they perceived care as being met with a friendly attitude and receiving adequate information and guidance during their examination. The patients did not expect any specific care measures or actions taken by the radiographers during their ordeal.

From the study, we conclude that the balance between the techno-science dimension and the human dimension is not an either-or question, nor is it about following a recipe. It has to be understood in a more nuanced, context-based sense. Patient involvement has many faces and as stated by Mol, good care is not just a matter of offering more choices to each patient. Our empirical data showed that care in radiographic practice, is more than simply a relation between human beings. We argue that care is a creative adaptive process attuning everything to everything including technologies, bodies and knowledge. We suggest Mols' concept of “tinkering” as a means of understanding how patient care is performed during diagnostic imaging procedures.

We have used our findings from interviews and observations to show how patients' perspectives may be involved to improve the quality of patient care in radiographic practice.

This study included five patients in FTICRP. To fully explore the involvement and care of these patients during diagnostic examinations, a larger study is needed.

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