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To see or not to see: a qualitative study of patients' views on their own diagnostic images

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Structured Abstract

Objectives – To ascertain what meaning individuals attach to perceiving images of their own interior body and how the images and their meanings affect the clinical consultation

Design-Face to face semi-structured interviews

Participants-25 adult patients in southern England who had recently been referred by their general practitioner (GP) for diagnostic imaging

Setting -Community

Results- For patients, being shown their own X-rays, magnetic resonance images (MRIs) or computed tomography (CT) images creates a variety of effects: 1) a sense of better understanding of the diagnosis; 2) validation of their sensory and emotional response to the illness or injury; and 3) an alteration to the tenor and nature of the clinical encounter between patient and physician. In addition to meanings attached to these images, patients also impute meaning to the physician's decision *not* to share an image with them. The desire to see their image was greater in those patients with a skeletal injury; patients are less keen on viewing abdominal or other soft-tissue images.

Conclusions-Viewing images of one's interior, invisible body is powerful and resonant in a number of ways. The experience of not seeing, whether through the patient's or the physician's choice, is also fraught with meaning.

Strengths and limitations of this study

- There has been no previous study exploring patients' reactions to seeing their own diagnostic images in consultation with their doctor.
- This study addresses the paucity of research involving diagnostic imaging in the context of clinical care rather than screening and preventative medicine. In addition, it addresses the largely neglected perspective of men viewing their own diagnostic images.
- The limitations were that we interviewed only patients. The physician's point of view and their reasons for deciding 'to share or nor to share' were not explored.

Introduction

Medical imaging is used in health care for diagnosis, screening and for monitoring of both disease progression and treatment response. In England alone there were 38,805,537 imaging investigations[i] conducted in the NHS during 2010/11 [1]. The armamentarium of imaging techniques has vastly expanded since Roentgen's discovery of X-rays in 1895, and the 'authority of the image' ([2]:20) has also, correspondingly, increased. In the present paper we begin to explore the meanings imputed to 'still' images when they are shared, or not shared, with patients, and so focus on computed tomography (CT) and magnetic resonance imaging (MRI) along with X-rays.

Development of digital imaging technology enables wider dissemination of images within medicine, and has changed the way these pictures are accessed and used clinically [3]. The literature on the role of medical imaging techniques concentrates on practitioners and institutions, and largely lacks the patient's viewpoint. A few exceptions are notable, including, the quite exceptional work by Blaxter, which dissects the author's own experience as a patient to explore the conflicting arguments about the ways in which medical technology, and in particular medical imaging, affect the management of illness and of doctor-patient relationships [4]. Blaxter describes how two opposing, or at least dialectic, tropes have prevailed in describing the effects of medical technology on patients. In one the medical image might be seen as the oppressor of the patient, creating a situation in which 'technological representations hide the selves embedded in human bodies' (p.763). In this view, patients are rendered passive in the face of a technology understood only by the experts; in their turn, medical experts' attitudes toward the pre-eminence and efficacy of

technology is reinforced by their patients' submissiveness to the authority of that technology.

An alternate perspective is propounded by Mol [5] and others, who argue that rather than being alienated by high-tech medical procedures, patients as well as practitioners enlist their outputs both to manage their perceptions of themselves and their ailments, and to influence their treatment. Taking this vantage point, the body is not subdued by the image, nor is the patient rendered invisible by it, but rather the body is 'multiplied' to include 'the image as well as the reality' ([4]:764). '[T]he recalcitrant public is an absent presence in many of the "problems with the public" in the public understanding of science.' Blaxter concludes that the alienation experienced by patients stems not from the technology or the images, but from the system in which both technology and the medical profession are bound: creating a case of problematic 'social adaptation' (p775). Apart from Blaxter's contribution, however, exploration of patients and their static images, in which they remain still and 'actively learn to be bodies' [6] and where the image production occurs remotely, is largely absent.

In addition, there has been an interesting thread in the medical anthropology and medical sociology literature exploring the role of women's experiences of particular procedures: screening mammography (see e.g. Kaufert [7]), antenatal foetal ultrasound (Sandelowski 1994a and b [8, 9]; Bricker et al 2000 [10]; Mitchell 2001[11], and bone densitometry [12-15]). There is however a paucity of research involving diagnostic imaging in the context of clinical care rather than screening and preventative medicine. In addition, reports of men's perspective on viewing their own diagnostic images are mostly neglected.

In a previous project, we queried general practitioners (GPs) and consultant radiologists (CRs) about the impact of sharing medical images with patients during consultations, and about the role of Picture Archiving and Communications (PACS) technology on the dissemination of diagnostic radiographic images beyond the hospital and into the arena of primary care [3]. In the current study, we shift the focus to the 'third leg' of the GP-consultant-patient tripod: the patient. Two central questions are addressed: i) what meanings do individuals attach to perceiving images of their own interior body? and ii) how do the images, and their meanings, affect the clinical consultation?

Methods

Twenty-five participants from nine practices in three primary care trusts (PCTs) in the south-east of England agreed to a semi-structured interview concerning their experiences of a recent referral from general practice for a diagnostic imaging (X-ray, CT, or MRI). We focused on these modalities as they produce a static image that is viewed separately, as opposed to the dynamic procedure of ultrasonography (cf. Radstake [6]). Participating practices issued invitations to patients who attended surgery and who met our participant criteria: adult, fluent speaker of English, competent to consent, and had been referred to an outpatient imaging department within the past 12 months. Written consent was gained prior to beginning the interview, which was audio-recorded and professionally transcribed. The interviews were conducted by LC, an anthropologist by training. Topics included patients' experiences of undergoing an imaging procedure, their attitudes toward the viewing or not viewing the resulting images, and their beliefs and opinions concerning the place of such images in a clinical consultation. Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Ref. no. 09/H1102/105).

All transcripts were read and coded by two researchers (LC and HS), manually by both researchers, and using a computer-assisted qualitative data analysis program *(NVivo)* by one researcher. Data were coded 'freehand' by creating as many new free nodes as seemed necessary, and then 'rolling up' nodes into hierarchies or trees. The freehand and the electronically-assisted coding produced very similar results. Memos recorded during the process of data collection and data analysis have also been incorporated into the presentation of findings.

Results

Twenty-five of 47 patients who expressed willingness to participate were interviewed; two potential participants changed their minds; the remainder were uncontactable, ineligible, or unavailable within the time frame of the project. Participants ranged from 41 to 86 years (mean age 65); nine (36%) were men. Most interviews were conducted in the participant's own home, but three individuals wished to be interviewed on university premises. Interviews ranged from 13 to 52 minutes, with a mean of 28 minutes.

The patients were recruited on the basis of having undergone a recent a primary care referral for a diagnostic imaging procedure. Of the 25 participants, 14 (56%) reported having been shown the focal referral image, and 23 (92%) spoke of *ever* having viewed images of themselves or of relatives (children, parents, spouses). In the results, to preserve anonymity, we use a convention of numbering plus an 'M' to indicate male and 'F' female participant.

What the images mean to patients

Patients' opinions, wishes, and thoughts on images 'being shared with' varied, as did the meanings they took away from the experience—or the lack of the experience—of viewing their own interior. The themes that emerged from our coding formed three identifiable but interwoven strands, namely that being shown images 1) enhances understanding of the problem , 2) affects the emotional impact of diagnosis, and 3) changes the nature of the interaction with the physician during consultation.

Firstly, the patients who viewed their own images reported that doing so **enhanced their understanding** of their ailments. Seeing the image *informed*; it served as a visual aid in a basic pedagogical sense. In addition (one thread) the image also validated sensation—*'that's why it hurts like it does'* (participant F13). In either case, the result of seeing the image produced or enlarged knowledge *by* the patient *of* her own corpus, it linked body to mind; several respondents commented that pain seemed easier to manage once they had seen its source 'for themselves'. F13 continues:

I think it was easy because then when he [physician] was talking about it and he could actually kind of point and see, so when someone is saying about the bottom disc missing from your spine you've got a vague idea of kind of where that is, but when you can actually look at it and he's pointing and showing you the different bits, and I think it actually helps you understand, it's not just some kind of airy fairy thing, it's actually there in front of you, and you can see it, and I think that's got to be a good thing.

F3 concurred, saying *'…if I had any fractures in the future I would want to see the fracture because I think it helps you understand the pain, if that makes sense…He [the consultant] wasn't hugely informative but I think the x-ray picture said it all.'* In some cases, the expectation of knowledge emanating from the image was very high indeed, and possibly unrealistic in its reach: *'…If I was able to see the x-ray I might have been able to see something that, you know, where the pain is, and say to the doctor "Well that's where I'm getting this pain, that area there." And they might be able to either explode that image up and see if there is anything in that actual area'* (M16).

In a second theme, viewing the image had an ***emotional impact***, generally one of reassurance, and not necessarily reliant on greater comprehension of the medical facts of the case. For instance M8 described viewing an image of his lungs: *'I think this a modern sort of thing isn't it now? Where patients get to see x-rays. Good thing for settling you down and making you feel calmer I think, and being aware that there's nothing wrong. I mean most people haven't got any medical knowledge at all have they, to be quite honest. So they could have been sideways, upside down, I wouldn't have known the difference.'* participants often spoke of the importance of having trust or faith in the physician, whether GP or speciaist, as being more important than seeing the image on which the doctor based his or her diagnosis or treatment recommendation: 'I've got faith in them, that their expertise is better than me looking at their pictures' (M8). Nonetheless, seeing the image for oneself offered reassurance for *some* participants. F23, commenting on a recent spinal X-ray, remarked: *'I was relieved that I could see definitely having had it pointed out to me, what was wrong, and it wasn't anything that I could have avoided myself, that it was just the*

bones had come together, trapped the nerves, that was it, and I could see for myself what had happened.' Other participants, however, felt added anxiety, as opposed to reassurance, about seeing an image that could convey bad news; for instance, a participant being investigated for possible lung cancer, F9, commented, *'I think it's a very grey area to want to see the X-ray if you don't know what you are looking for ….'.* M21 expressed a quite certain opposition to viewing his hip X-ray: *'…no, I don't think so, no, no, I don't want to look at it, I don't think so. I mean I don't want to see it to be honest… If it's bad I don't want to see it, you know, I can feel that it's not good, I know it's not good so I'll take that as evidence'*.

Finally, the third thematic strand in our analysis focuses on the impact of shared viewing of the medical image as ***changing the nature of the consultation with the physician***. Again, this theme comprises multiple threads. In one, we elucidate the manner in which the physical presence of the image serves as a focal point for both doctor and patient, changing the consultation dynamic. An example: F6, discussing her hip and lower spine X-ray, enthused, *'but to actually see it as a patient I think is invaluable really, I think it would be marvellous, and also in terms of mediating the relationship with your doctor because we're talking about a third thing, rather than it being… face to face…'*. This patient, an articulate woman familiar with medical argot and medical practitioners, finds comfort in having the image serve as a point of common interest, rather than she, as the patient, being the sole focus of the medical gaze. For other participants, the image almost becomes a third 'actor', more than a 'thing', within the room, exemplified by several quotes beginning *'The x-ray says*'; for instance, *'[T]he X-ray says arthritis'* (M24). The image, however, may attract the attention of the physician at the expense of the attention paid to the actual patient in the room, or, as in the case of participant M24, give the impression that the physician's opinion is at odds with the diagnosis 'made' by the image: *'I could tell he didn't quite agree with this X-ray. But he didn't say that. They don't say, "I don't agree with it."'*

The very decision made by the physician as to *whether* to show the image to the patient affects the way the patient understands the relationship between themselves and the doctor. Respondents with whom the doctor had deliberately shared an image felt more part of the consultation, and sometimes of the treatment decisions. They also felt more respected and valued by their doctor, both because to share the image took more time than not to, and because the expectation of interest, even without comprehension, in the

anatomical facts suggested that the doctor had a high opinion of the patient as a person. The act or fact of sharing implied respect and concern *'…because you feel they've taken the time to show you. You feel they care a lot'* (M24). F1, suffering from an abdominal complaint, commented:

> *I suppose it would be- yes, very sort of empowering in a kind of way if somebody had time to say "This is the X-ray, this is the thing we found, this is where the disintegration is but this bit's all right." I think yes it would be good, but I think it would so far exceed my expectations because of the lack of time that people have that it wouldn't even come into my head to think that it might be possible.*

M16 talks about his experience of seeing X-rays of his hip and shoulder, saying *'I think it brings you a little bit closer to the doctor and a bit more rapport with them. That's what I just feel.'* However, the effect of the clinician's decision about shared viewing of an image is perhaps conveyed most clearly by the comments of participants whose doctors chose *not* to share with them an image which the doctor was currently scrutinising. M24, speaking of his hip and spine X-ray, said *'[In]… fact I didn't ask because I don't think I'd know anything about it anyway. I wouldn't know anything on the X-ray. He could tell me, but I just felt – I didn't ask, so he wasn't going to show it'*. This respondent had caught a brief glimpse of the image on the doctor's monitor, which the doctor gazed at during the consultation, *'It's white, it's a light, it attracts your eye'*. This respondent disparaged his own intelligence when trying to explain why his doctor denied him a look at the image himself: *'I guess he has pressure, his other patients. And, but yes, he's very good. He would answer any questions I asked him. It's only our ignorance that we don't know what to ask…'*. From our interview, it is clear that this man had wit enough to ask thoughtful questions about his spinal disc problem and in response to a question about why he wanted to view the image, he replied, *'I suppose it makes you feel a little bit more involved, a bit more interested, or a bit more involved in what's going on inside you, because it is your body. They would be sort of, kind of added extras. I could have come out and said, "Do you know what, they've showed me my back."'* Another respondent, F9, reported noticing a CT image of her kidneys on the monitor on her doctor's desk. *'And I was sort of looking at it, and he went "Oh, that's not for you to see" and turned the screen, the computer screen [away]'*. Other respondents expressed concern about the added time it would take their doctor to

show and explain the image. F22 felt that she would like to view images of her foot X-ray, but commented: *'It would be interesting yes, but I would think it's a time factor with lots of doctors having to stop and show people and explain everything.'* M24 concurred with respect to his lower back and pelvic image: '*If he had shown me the X-ray and I could have been a person that wanted to know every little detail of it and it could have been five, ten minutes explaining. But he's got a pressure of a queue outside waiting to come in.*'

Variation and trends in responses

Participants provided mixed responses about wanting to view their images. No particular pattern emerged regarding age or sex in this regard, but we found a trend with respect to anatomy: patients were more eager to view pictures of the skeleton, whereas soft tissue, especially abdominal organs, elicited a higher level of squeamishness and a reduced desire to view the image. F11 expressed huge enthusiasm about viewing x-rays of her spine, but added, *''I'm not saying I'd want to look at my own tummy, you know, but to look at an x-ray is brilliant'*—x-ray clearly connoting 'bones' to her. On the other hand, M26 (our pilot interview, not included in the main dataset) commented that bony x-rays serve as a reminder of mortality, in contrast to, for instance, antenatal ultrasound, which the respondent characterized as being '*completely different*', and '*about life'*. The desire or lack of desire to see one's own image was also linked for some with the seriousness of the ailment, or the danger of planned procedure. One participant, F23, discussed her examination for two ailments, one respiratory and one spinal. She feared the effects of her spinal problem more than her respiratory complaint and thus felt a greater desire to view for herself the image of her spine: *'…I wasn't worried about wheezing with my chest, I mean I know it could be serious, but I didn't think it was serious, but I was very worried about my spine because I was worried I would be like it for the rest of my life…'*.

Some participants felt that viewing the image was wasted time, their own and the practitioners'; F20, who had undergone a neck X-ray for persistent pain, probably arthritic, felt only added frustration at viewing the image in the company of her specialist nurse-practitioner: *' …no, I mean if you don't know what you're looking at then it's not really very helpful is it'*. F2, aged 81, consulted her GP for a problem with her spine, and also discussed

an experience getting an X-ray for a foot injury. She felt that it might be *'interesting'* to see the image, but went on to say

'Well really you rely on the doctor don't you to advise and you just go along with that, so you're hoping that you're getting the right medication.... I mean they've been through all their learning haven't they, and degrees and such like, and they know better than I do, hopefully'.

F3, who felt strongly that she better understood and dealt with her pain from a fractured thumb because she had viewed the X-ray herself, also commented on the importance of trusting the doctor, who told her he was *'happy with the positioning of the fracture'*. The positioning as viewed on the X-ray did not look right to F3, who said *'…We were slightly confused … but you're trusting that the doctor knows what he's talking about, so that was really it, that was basically what he said…'*.

Discussion

Statement of principal findings

While clinicians order diagnostic imaging with the aim of adding to their information about a patient's complaint, the images themselves, and their production, do more than convey clinical data. For our research participants, adults aged 40 and above living in the south of England who had recently undergone diagnostic imaging, the static medical image occupies multiple positions: it enhances the patient's understanding of his or her complaint; it has the potential for emotional impact (positive and negative), and it affects the nature of the doctor-patient encounter. The three themes identified in the data highlight the symbolic meanings attaching to *the act of viewing* the images alongside the doctor: 1) greater comprehension of the illness or injury; 2) the emotional effect linked to viewing one's 'invisible body'; and 3) the influence of shared viewing of the image on the social dynamic of the medical consultation. Our data show that viewing one's interior, invisible body can be powerful and resonant.

Strengths and weaknesses of the study

Unlike any previous study we have found, this investigation included both men and women, and took a patient-centred perspective focusing on the *process* of sharing images in a clinical consultation, rather than taking a medicalised, illness-centric stance enquiring about a particular ailment or procedure. Weaknesses include the limited age range of our population; all the adults were 40 years or older, with an average age of 65 years. It would be interesting to find out what a younger generation of patients thinks about the experience of viewing their own medical images. Finally, our study did not incorporate the viewpoint of the patient's doctor. (Our previous did address this question, though not via the these patients' clinicians [3])

Strengths and weaknesses in relation to other studies, discussing important differences in results

We are informed by prior research into particular diagnostic sub-groups and specific technologies (e.g. older women and bone densitometry [12]; pregnancy and ultrasound [16], mammography [17] and hysteroscopy [18]). All of these studies focus on women. Cohn [19] explores neurological or psychiatric patients their understanding of their brain scans. Radstake [6] conducted what she calls 'endography' (i.e. an inner-looking take on 'ethnography') of patients undergoing real-time imaging in a Dutch hospital. A recurrent theme in this stream of literature is a sense of patients' discomfort with the imaging and with technology more generally. Reventlow et al. [13-15] working with Danish women in their 60s, noted that the highly technological nature of the investigation created in these *asymptomatic* women a sense of weakness and vulnerability. Griffiths et al. [17] explored women's perspectives on breast screening and mammogram, again finding that the visualisation technology imposes on women a devaluation of their own breast and body awareness, 'separating the at-risk breast from embodied experience'. Our work, however, suggests that for some patients, in some situations, viewing their own images generates an almost opposite reaction, one of enhanced empowerment and of reassurance.

Van Dijck writes that 'patients often blindly trust the panoptic nature of the mechanical-clinical eye' ([20]: 8). In this study, we find otherwise; patients are neither blindly trusting nor entirely certain of the role of the image in clinical care, but are, like their doctors, finding their way through the information available to the best possible solution for them. Merleau-Ponty [21, 22] argues that perception is an embodied experience; that viewing images, in the case of one's self, becomes incorporated into the individual's sense of himself or herself. Cohn [23] reports that patients who chose to view images from their brain scans regarded the image as validating the sensation, the experience of mental illness. Where other forms of communication like reports and numerical data seem inaccessible, and perhaps inapplicable, the picture itself embodies and thus represents in a simple and, according to Cohn, 'autonomous' manner the mental illness and consequent suffering of that particular patient. In the present study, we have explored the role of the image in dealing with physical illness and injury.

Meaning of the study: possible explanations and implications for clinicians and policy makers

Our own previous research suggests that physician opinion about sharing images with the patients varies, and that the reasons for the decision 'to share or not to share' range from the logistic to the philosophical. Mol (2002) [5] writes that x-rays are done 'one body at a time'; our aim in this project has been to understand the perspectives of people whose bodies, one at a time, were investigated. We have described both positive and negative attitudes of these respondents toward seeing images of the interior body. These affective responses around the viewing of images, however, are not uncomplicated or unmitigated; more cognitive considerations also come into play, including which part of the body has been imaged, the nature of the ailment, and indeed the nature of the patient. Thus we cannot reach simple conclusions or make recommendations as to whether and when sharing images with patients promote a good outcome. We can however, with our data, stimulate discussion amongst clinicians who will be increasingly faced with the opportunity to share visual evidence of health and disease with their patients.

Underscoring the resonance of the research findings, nearly everyone- colleagues, friends, family, casual acquaintances-with whom the first author discussed this project, whether in a social or an academic milieu, responded immediately by recounting a personal experience of undergoing imaging procedures and viewing (or not viewing) the resulting images. Literally everyone had a story, often told with great emotion, and an opinion on how the consultation benefited or suffered from the manner in which the image was, or was not, shared by the physician. Everyone is a patient.

Unanswered questions and future research

The clinical encounter takes place, usually, in a dyadic form; in the present study, we queried only one half of the dyad with respect to the experience of viewing or not viewing a particular image. These physician's own point of view, his or her own reasons for deciding 'to share or not to share', remain opaque to us, reported if at all only by conjecture or hearsay on the part of our research subjects. An investigation involving both halves of the pair would be a very useful addition to the project.

Another, almost completely unexplored component of medical imaging is the role of the technician or technologist: the individual who makes the image. Some of our participants reported significant encounters with the technician, both in terms of the

experience of producing the image, and in terms of learning something of the results. Current guidelines regarding patient-technician interactions allow for leeway depending on the seniority and position of the technician. Some physicians spoke quite dismissively of the technician's role, seeing the person as a mere extension of the machinery. Informal and unstructured preliminary investigation suggests that in fact, this is far from the truth of the situation. Further exploration of the technician's role regarding patient viewing of images would be of interest.

Competing interest statement

All authors have completed the Unified Competing Interest form atwww.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work [or describe if any]; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years [or describe if any], no other relationships or activities that could appear to have influenced the submitted work [or describe if any].-

Contributorship statement

Leslie Carlin (LC), Flis Henwood (FH) and Helen Smith (HS) developed the study idea and method. LC conducted the interviews. LC and HS read and coded the transcripts and interpreted the data. LC drafted the paper and HS and FH provided constructive feedback on all versions of the manuscript. Helen Smith is the guarantor of this paper.

Transparency declaration

Helen Smith (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained

Ethical approval

Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Reference number 09/H1102/105)

Details of funding

There was no external funding for this project

Data sharing

No additional data available

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Research Checklist

This checklist includes the original protocol and a COREC check list

Provisional research plan: patient perspective of viewing images (PACS and patients = PaP)

Principal and secondary research questions:

1. 'How does viewing their own radiograph or other scan as part of a clinical consultation affect patients?'

2. Secondary objectives include 1) exploration of the valence of any effect (positive or negative) of having viewed the image during a consultation; 2) investigation of constructive 'after effects' of viewing such an image, e.g. around comprehension of a diagnosis or compliance with treatment.

Summary of study:

This research project is designed to explore the impact on patients of viewing their own radiologic images: mainly x-rays, but also MRIs and CT scans. There is a dearth of information available about how sharing x-ray and other radiologic images with patients affects the clinical consultation. Currently in the UK, a GP may refer a patient to radiology services for investigation of a problem; a radiologist then views the image and sends a report back to the referring physician for discussion of diagnosis and any treatment. Increasingly with the advent of Picture Archiving and Communications Systems (PACS) within the NHS, it is feasible that the image will accompany the report, and the GP will be able to share both information and image with his or her patients. We wish to investigate the impact of 'sharing images with patients' (SIP) on the patient and more generally on the patient journey. There is a large literature concerning the use of digital radiologic images for diagnosis and teaching within medicine, and for remote medical care, but relatively little on the impact of sharing such images with patients themselves. What research exists, has been conducted with regard to specific health issues in women at particular life stages, e.g. bone densitometry scans, mammography, or fetal ultrasonography. Research on health literacy has reviewed the use of pictorial modes of communication and found them to be of great use in some circumstances, so it is reasonable to think that images of their own bodies will be effective in communicating with patients. Our previous research investigated consultant radiologists' and GPs' views on PACS in a previous study; our current aim is thus to explore the third 'leg' of the 'tripod': patients' perspectives on a) viewing their x-rays, b) the role of x-rays in the 'patient journey', and c) experience of x-ray services.

Summary of main issues:

The main ethical issues revolve around a) being sensitive to participants' own concerns that are distinct from our research interests and b) maintaining privacy and confidentiality. Point

Research Checklist

(a) will be addressed by targeting patients who are unlikely to be in situations that arouse particular alarm (i.e. in non-acute and non-life-threatening condition). To maintain privacy and confidentiality (point b), utmost care will be taken to conduct interviews in private, to use coding to protect identities, and to destroy and discard any personal or identifying information pertaining to individuals who may be contacted but decline to participate.

Scientific justification:

With film x-rays, the typical route for a patient referred from primary care involved a picture being viewed by a radiologist or other specialist, followed by a report transmitted to the GP, who fed back to the patient based on a written report. With the advent of PACS and filmless technology, the roll-out of PACS to primary care settings is in process. Once this is in place, it is envisioned that both report and image will be transmitted to the primary care physician. How will this affect the consultation? In what situations is the visual imagery useful, or perhaps detrimental? In our previous research, we explored the attitudes and beliefs of GPs and of consultant radiologists toward this 'sharing of images with patients' (SIP); our analysis suggests that both benefits and drawbacks accrue to the general practitioner from such a system. To our knowledge, no exploration has as yet been conducted about the impact of viewing their own radiographic image on patients within a consultation; the current project is designed to remedy that omission.

The proposed project is an outgrowth of previous research which was approved and funded by the Brighton and Sussex Medical School [details], results of which have been presented at professional conferences and are currently under review for a scientific journal. The research questions to be addressed here are of a developmental nature and are intended to lead to an application for a grant in the near future.

Design and methods:

We intend to recruit patients referred to the imaging service from primary care at the outpatient clinic, either polyclinic or hospital outpatient facility. Patients will be asked either while waiting for their appointment, or just afterward, whether they would consider talking with a researcher after receiving their results, about their experience of undergoing an x-ray [or other procedure] and about the subsequent consultation. An information leaflet with contact details will be provided, and it will be made clear that opting out at any time is possible.

Participants in the study will be recruited from those patients referred by GPs for outpatient x-ray or scan procedures. A small number (yet to be determined) of GP surgeries will be invited to cooperate in this developmental phase, and cooperating GPs will ask patients who meet the inclusion criteria whether a researcher may contact them by phone, post, or email after their imaging procedure. If the patient agrees, a researcher (LC) will contact them by the agreed method some time after their procedure to arrange an interview. A consent form will be sent to them prior to the arranged meeting, and the interview will proceed only after the consent form is signed. Thus consent will be obtained in a two-stage process: first, consent for the researcher to contact the participant at an appropriate date, and second, consent to being interviewed.

Research Checklist

We will request contact details for those who agree to participate, and will contact them by their preferred route (phone, post, or email) about a week after the procedure, to catch them as soon after any follow-up consultation as possible.

We anticipate a developmental phase to the study in which semi-structured interviews with the first 3 or 4 patients will frame a series of questions to be consistently included in interviews with the formal sample of approximately 25 patients.

In our previous project, we found that interviews with just over 30 individuals in two professional groups (GPs and radiologists) gave us data saturation; further data collection was unlikely to provide new information. Since the aim of this research is to develop a broad outline of the experience of viewing medical images, we feel that a similar point of data saturation will be reached with 25-30 participants. Reventlow et al. (2006) describe a study of women learning their results of a bone density scan by viewing charts and images; in that project, 16 respondents were included. Because we anticipate interviewing patients some of whom have and some who have not viewed their own radiologic images, we are aiming for a higher total number.

Interviews are anticipated to last approximately 30 minutes; they will be conducted by Dr. Leslie Carlin; location will be flexible for convenience of participants (most likely to be face-to-face in a GP surgery if room available, alternatively, at the university, or in patient's home, or by telephone.

Initial questions we wish to include:

* Introduce our research as being about the use of x-rays or scans in consultations
* Name, age, gender, birthplace [if non-local, how long living in Sussex- see below]
* For what complaint were you referred to the hospital/clinic for an x-ray/scan?
* What sort of information were you given by the technician who took the x-ray/scan?
* How long was the wait if any between referral, procedure, and learning results?
* If you met with someone to discuss your results, who did you meet, and where?
* How was that information presented [probe for clarity, sympathy, patience]?
* Did [whoever] show you the x-ray/scan during your consultation? if yes:
  * Did you think it was a good thing to be able to see the picture of your [blank]? If yes, why? If no, why not?
  * Did [whoever] use the picture in his/her explanation to you about your results? If yes, in what way was the picture useful?
* [if relevant, may follow up with questions about similar procedure in place of origin]

The data will be transcribed and all transcripts read by one researcher (LC). The transcripts will be entered into NVivo, a computer-assisted qualitative data analysis program, which facilitates creative consideration and evaluation of verbal data in a variety of ways, and also serves as a tool for developing draft reports. The theoretical perspective will make sensible use of a grounded theory approach (taking the data as they come, without preconceptions) but will also take on board Merleau-Ponty's (1962) argument that perception is an embodied experience, i.e. that viewing images, in this case of one's self, becomes incorporated into the individual's sense of himself or herself.

Involvement of patients and service users:

Research Checklist

The set of interview questions will be trialled on the first few respondents and the interview schedule reviewed modified if necessary. All participants (who are both patients and service users) will be essential in managing and undertaking the research, as only their cooperation will drive it forward. As this is a qualitative study, analysis relies on the patients responding in a thoughtful and analytic manner to our proposed questions. Finally, all participants will be offered the opportunity to receive their own lay account of findings in writing, or to meet with the researchers in person.

Inclusion/exclusion criteria:

Inclusion: adult patients referred by their GP for outpatient X-ray. Exclusion: patients who cannot give own consent (some learning disabled or psychiatric patients); patients deemed by the referring GP as vulnerable; patients whose referral is deemed by the referring GP to be for reasons that are likely to be traumatic.

Risks and risk management:

Potential risks and burdens to respondents include the intrusion of contact with a researcher, and possible distress at re-living an uncomfortable experience. We will not encourage people to participate in the project unless they are freely willing, and will clarify that they may withdraw at any point, even mid-interview. The interviewer is an anthropologist experienced at conducting face-to-face research who will use her own judgement to as well to ascertain that participants are comfortable being part of the project.

Interviews will be conducted in a location agreed by both participant and researcher, designed to be comfortable for the participant. Attention to privacy will be foremost although we remain sensitive to the fact that for some respondents, company might be desirable. The interviewer (Dr. Leslie Carlin) is an anthropologist and is experienced at discussing unusual topics with people. The interview is semi-structured, so that respondents will be able to guide the discussion in a direction that is comfortable to them- there are no questions that they have to answer. Privacy and confidentiality will be maintained throughout data collection, analysis, and reporting.

Risks to researchers are minuscule, and are limited to personal security in certain interviewing situations. The risk can be minimised by utilising an automated security reporting system (CRYSIS). Common sense will prevail, and if the interviewer feels threatened or even uncertain, she will abort the meeting.

Confidentiality and data protection:

Participants will be pseudonymised and a coded key kept electronically in a password-protected location. Any paper notes that include personal data will be stored in a locked filing cabinet in a locked office in a secure building on the university campus.

Information will be stored on password-protected computer accounts held and secured by the University of Brighton. Any work on this information done from the researcher's home can also be done via a secure network directly to the the university system, so that no personal data relating to participants need be stored on home computer or laptop. Paper-based information will be stored in a locked filing cabinet in a locked (when unoccupied) office, in a secure building on the university campus.

Research Checklist

It is likely that personal and potentially identifying information will be stored on and transferred between work (university) and home computers, via email or other network. Direct quotations may be used in reports and publications. Address or phone numbers will most likely be used for contacting participants and for making arrangements to meet. The interviews will be audio-taped for later transcription.

Paper data will be stored in locked filing cabinets; electronic files in a password-protected account belonging to Prof. Helen Smith, on the university's mainframe computer. Data will be stored for up to 10 years, as it is hoped that this project will generate a further program of work.

Research Checklist

Transparency declaration Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

Table 1
Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*
8.	Interviewer characteristics Table 1	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		

Research Checklist

No	Item	Guide questions/description
		interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned No	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking No	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

Research Checklist

No	Item	Guide questions/description
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? *e.g. face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? *e.g. home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the

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To see or not to see: a qualitative study of patients' views on their own diagnostic images

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To see or not to see: a qualitative interview study of patients' views on their own diagnostic images

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Structured Abstract

Objectives - To ascertain what meaning individuals attach to perceiving images of their own interior body and how the images and their meanings affect the clinical consultation

Design - Face to face semi-structured interviews

Participants - 25 adult patients in southern England who within the preceding 12 months had been referred for diagnostic imaging

Setting - Community

Results - For patients, being shown their own X-rays, magnetic resonance images (MRIs) or computed tomography (CT) images creates a variety of effects: 1) a sense of better understanding of the diagnosis; 2) validation of their sensory and emotional response to the illness or injury; and 3) an alteration to the tenor and nature of the clinical encounter between patient and physician. In addition to meanings attached to these images, patients also impute meaning to the physician's decision *not* to share an image with them. The desire to see their image was greater in those patients with a skeletal injury; patients are less keen on viewing abdominal or other soft-tissue images.

Conclusions - Viewing images of one's interior, invisible body is powerful and resonant in a number of ways. The experience of not seeing, whether through the patient's or the physician's choice, is also fraught with meaning.

Article summary

Article focus

- There is a paucity of research involving diagnostic imaging in the context of clinical care rather than screening and preventative medicine. In addition, reports of men's perspective on viewing their own diagnostic images are mostly neglected. There has been no previous study exploring patients' reactions to seeing their own diagnostic images in consultation with their doctor.

Key messages

- The viewing their own static images create for patients a variety of effects: 1) a sense of better understanding of the diagnosis; 2) validation of their sensory and emotional response to the illness or injury; and 3) an alteration to the tenor and nature of the clinical encounter between patient and physician.
- In addition to meanings attached to these images, patients also impute meaning to the physician's decision *not* to share an image with them. The desire to see their image was greater in those patients with a skeletal injury; patients are less keen on viewing abdominal or other soft-tissue images.

Strengths and limitations

- Weaknesses include the limited age range of our population; all the adults were 40 years or older, with an average age of 65 years. It would be interesting to find out what a younger generation of patients thinks about the experience of viewing their own medical images.
- The data were collected retrospectively and are thus reliant on participants' recall. We queried only one half of the clinician-patient dyad with respect to the experience of viewing or not viewing a particular image. These physician's own point of view, his or her own reasons for deciding 'to share or not to share', remain opaque to us, reported if at all only by conjecture or hearsay on the part of our research participants.

Introduction

Medical imaging is used in health care for diagnosis, screening and for monitoring of both disease progression and treatment response. In England alone there were 38,805,537 imaging investigations[i] conducted in the NHS during 2010/11 [1]. The armamentarium of imaging techniques has vastly expanded since Roentgen's discovery of X-rays in 1895, and the 'authority of the image' [2] (page 20) has also, correspondingly, increased. In the present paper we begin to explore the meanings imputed to 'still' images when they are shared, or not shared, with patients, and so focus on computed tomography (CT) and magnetic resonance imaging (MRI) along with X-rays.

Development of digital imaging technology enables wider dissemination of images within medicine, and has changed the way these pictures are accessed and used clinically [3]. The literature on the role of medical imaging techniques concentrates on practitioners and institutions, and largely lacks the patient's viewpoint. A few exceptions are notable, including, the quite exceptional work by Blaxter, which explores her own experience as a patient looking for conflicting arguments about the ways in which medical technology, and in particular medical imaging, affect the management of illness and of doctor-patient relationships [4]. Blaxter describes how two opposing tropes have prevailed in describing the effects of medical technology on patients. In one the medical image might be seen as the oppressor of the patient, creating a situation in which 'technological representations hide the selves embedded in human bodies' (page 763). In this view, patients are rendered passive in the face of a technology understood only by the experts; in their turn, medical

experts' attitudes toward the pre-eminence and efficacy of technology is reinforced by their patients' submissiveness to the authority of that technology.

An alternate perspective is propounded by Mol [5] and others, who argue that rather than being alienated by high-tech medical procedures, patients as well as practitioners enlist their outputs both to manage their perceptions of themselves and their ailments, and to influence their treatment. Taking this vantage point, the body is not subdued by the image, nor is the patient rendered invisible by it, but rather the body is 'multiplied' to include 'the image as well as the reality' [4](page 764). '[T]he recalcitrant public is an absent presence in many of the "problems with the public" in the public understanding of science.' Blaxter concludes that the alienation experienced by patients stems not from the technology or the images, but from the system in which both technology and the medical profession are bound: creating a case of problematic 'social adaptation' (page 775). Apart from Blaxter's contribution, however, exploration of patients and their static images, in which they remain still and 'actively learn to be bodies' [6] and where the image production occurs remotely, is largely absent.

In addition, there has been an interesting thread in the medical anthropology and medical sociology literature exploring the role of women's experiences of particular procedures: screening mammography ([7]), antenatal foetal ultrasound [8 - 11], and bone densitometry [12-15]. There is however a paucity of research involving diagnostic imaging in the context of clinical care rather than screening and preventative medicine. In addition, reports of men's perspective on viewing their own diagnostic images are mostly neglected.

In a previous project, we queried general practitioners (GPs) and consultant radiologists about the impact of sharing medical images with patients during consultations, and about

the role of Picture Archiving and Communications (PACS) technology on the dissemination of diagnostic radiographic images beyond the hospital and into the arena of primary care [3]. In the current study, we shift the focus to the 'third leg' of the radiologist-clinician - patient tripod: the patient. Two central questions are addressed: i) what meanings do individuals attach to perceiving images of their own interior body? and ii) how do the images, and their meanings, affect the clinical consultation?

Methods

Participants and sampling

Twenty five patients from nine general practices in the south-east of England participated in this study (Table 1). A convenience sampling strategy was used, participants were recruited by eleven general practitioners who during the consultation enquired of the patients' willingness to participate in a semi-structured interview concerning their experiences of a recent referral from general practice for diagnostic imaging (X-ray, CT, or MRI). We focused on these modalities as they produce a static image that is viewed separately, as opposed to the dynamic procedure of ultrasonography (cf. Radstake [6]). The study inclusion criteria were: adult, fluent speaker of English, competent to consent, and had been referred to an outpatient imaging department within the past 12 months.

Interview procedure

Written consent was gained prior to beginning the interview, which was audio-recorded and professionally transcribed. All interviews were conducted by LC, an anthropologist by training. Topics included patients' experiences of undergoing an imaging procedure, their attitudes toward the viewing or not viewing the resulting images, and their beliefs and opinions concerning the place of such images in a clinical consultation. Descriptive (interview setting, participant behaviours) and reflective field notes were made during the interview process.

Analysis

Data were analysed following a qualitative descriptive method [16]. All transcripts were read and coded by two researchers (LC and HS), manually by both researchers, and using a computer-assisted qualitative data analysis program *(NVivo)* by one researcher (LC). Data were coded 'freehand' by creating as many new free nodes as seemed necessary, and then 'rolling up' nodes into hierarchies or trees. The freehand and the electronically-assisted coding produced very similar results.

Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Ref. no. 09/H1102/105).

Results

Twenty-five of 47 patients who expressed initial willingness to participate were interviewed; two potential participants changed their minds; the remainder were uncontactable, ineligible, or unavailable within the time frame of the project. Participants ranged from 41 to 86 years (mean age 65); nine (36%) were men. At the request of the ethics committee we did not count or collect information about the participants who declined the GPs invitation to participate. Most of the interviews were conducted in the participant's own home, but three individuals wished to be interviewed on university premises. Interviews ranged from 13 to 52 minutes, with a mean of 28 minutes.

While the patients were recruited on the basis of having undergone a recent diagnostic imaging procedure, sometimes other experiences of imaging also formed part of the discussion, for example earlier imaging experiences of themselves or others. Of the 25 participants, 14 (56%) reported having been shown the image that rendered them eligible for this study, and 23 (92%) spoke of how on some other occasion they had viewed images of themselves or of relatives (children, parents, spouses) (Table 1). In the results, to preserve anonymity, we use a convention of numbering participants, prefixed with 'M' to indicate a male and 'F' a female participant.

What the images mean to patients

Patients' opinions, wishes, and thoughts on images 'being shared with' varied, as did the meanings they took away from the experience—or the lack of the experience—of viewing their own interior. The themes that emerged from our coding formed three identifiable but interwoven strands, namely that being shown images 1) enhances understanding of the problem , 2) affects the emotional impact of diagnosis, and 3) changes the nature of the interaction with the physician during consultation.

Firstly, the patients who viewed their own images reported that doing so **enhanced their understanding** of their ailments. Seeing the image *informed*; it served as a visual aid in a basic pedagogical sense. In addition (one thread) the image also validated sensation—*'that's why it hurts like it does'* (participant F13). In either case, the result of seeing the image produced or enlarged knowledge *by* the patient *of* her own corpus, it linked body to mind;

several respondents commented that pain seemed easier to manage once they had seen its source 'for themselves'. F13 continues:

> *I think it was easy because then when he [physician] was talking about it and he could actually kind of point and see, so when someone is saying about the bottom disc missing from your spine you've got a vague idea of kind of where that is, but when you can actually look at it and he's pointing and showing you the different bits, and I think it actually helps you understand, it's not just some kind of airy fairy thing, it's actually there in front of you, and you can see it, and I think that's got to be a good thing.*

F3 concurred, saying *'…if I had any fractures in the future I would want to see the fracture because I think it helps you understand the pain, if that makes sense…He [the consultant] wasn't hugely informative but I think the x-ray picture said it all.'* In some cases, the expectation of knowledge emanating from the image was very high indeed, and possibly unrealistic in its reach: *'…If I was able to see the x-ray I might have been able to see something that, you know, where the pain is, and say to the doctor "Well that's where I'm getting this pain, that area there." And they might be able to either explode that image up and see if there is anything in that actual area'* (M16).

In a second theme, viewing the image had an ***emotional impact***, generally one of reassurance, and not necessarily reliant on greater comprehension of the medical facts of the case. For instance M8 described viewing an image of his lungs: *'I think this a modern sort of thing isn't it now? Where patients get to see x-rays. Good thing for settling you down and making you feel calmer I think, and being aware that there's nothing wrong. I mean most people haven't got any medical knowledge at all have they, to be quite honest. So they could have been sideways, upside down, I wouldn't have known the difference.'* participants often spoke of the importance of having trust or faith in the physician, whether GP or specialist, as being more important than seeing the image on which the doctor based his or her diagnosis or treatment recommendation: 'I've got faith in them, that their expertise is better than me looking at their pictures' (M8). Nonetheless, seeing the image for oneself

offered reassurance for *some* participants. F23, commenting on a recent spinal X-ray, remarked: *'I was relieved that I could see definitely having had it pointed out to me, what was wrong, and it wasn't anything that I could have avoided myself, that it was just the bones had come together, trapped the nerves, that was it, and I could see for myself what had happened.'* Other participants, however, felt added anxiety, as opposed to reassurance, about seeing an image that could convey bad news; for instance, a participant being investigated for possible lung cancer, F9, commented, *'I think it's a very grey area to want to see the X-ray if you don't know what you are looking for ….'.* M21 expressed a quite certain opposition to viewing his hip X-ray: *'…no, I don't think so, no, no, I don't want to look at it, I don't think so. I mean I don't want to see it to be honest… If it's bad I don't want to see it, you know, I can feel that it's not good, I know it's not good so I'll take that as evidence'*.

Finally, the third thematic strand in our analysis focuses on the impact of shared viewing of the medical image as ***changing the nature of the consultation with the physician***. Again, this theme comprises multiple threads. In one, we elucidate the manner in which the physical presence of the image serves as a focal point for both doctor and patient, changing the consultation dynamic. An example: F6, discussing her hip and lower spine X-ray, enthused, *'but to actually see it as a patient I think is invaluable really, I think it would be marvellous, and also in terms of mediating the relationship with your doctor because we're talking about a third thing, rather than it being… face to face…'*. This patient, an articulate woman familiar with medical argot and medical practitioners, finds comfort in having the image serve as a point of common interest, rather than she, as the patient, being the sole focus of the medical gaze. For other participants, the image almost becomes a third 'actor', more than a 'thing', within the room, exemplified by several quotes beginning *'The x-ray says*'; for instance, *'[T]he X-ray says arthritis'* (M24). The image, however, may attract the attention of the physician at the expense of the attention paid to the actual patient in the room, or, as in the case of participant M24, give the impression that the physician's opinion is at odds with the diagnosis 'made' by the image: *'I could tell he didn't quite agree with this X-ray. But he didn't say that. They don't say, "I don't agree with it."'*

The very decision made by the physician as to *whether* to show the image to the patient affects the way the patient understands the relationship between themselves and the doctor. Respondents with whom the doctor had deliberately shared an image felt more part

of the consultation, and sometimes of the treatment decisions. They also felt more respected and valued by their doctor, both because to share the image took more time than not to, and because the expectation of interest, even without comprehension, in the anatomical facts suggested that the doctor had a high opinion of the patient as a person. The act or fact of sharing implied respect and concern *'…because you feel they've taken the time to show you. You feel they care a lot'* (M24). F1, suffering from an abdominal complaint, commented:

> *I suppose it would be- yes, very sort of empowering in a kind of way if somebody had time to say "This is the X-ray, this is the thing we found, this is where the disintegration is but this bit's all right." I think yes it would be good, but I think it would so far exceed my expectations because of the lack of time that people have that it wouldn't even come into my head to think that it might be possible.*

M16 talks about his experience of seeing X-rays of his hip and shoulder, saying *'I think it brings you a little bit closer to the doctor and a bit more rapport with them. That's what I just feel.'* However, the effect of the clinician's decision about shared viewing of an image is perhaps conveyed most clearly by the comments of participants whose doctors chose *not* to share with them an image which the doctor was currently scrutinising. M24, speaking of his hip and spine X-ray, said *'[In]… fact I didn't ask because I don't think I'd know anything about it anyway. I wouldn't know anything on the X-ray. He could tell me, but I just felt – I didn't ask, so he wasn't going to show it'*. This respondent had caught a brief glimpse of the image on the doctor's monitor, which the doctor gazed at during the consultation, *'It's white, it's a light, it attracts your eye'*. This respondent disparaged his own intelligence when trying to explain why his doctor denied him a look at the image himself: *'I guess he has pressure, his other patients. And, but yes, he's very good. He would answer any questions I asked him. It's only our ignorance that we don't know what to ask…'*. From our interview, it is clear that this man had wit enough to ask thoughtful questions about his spinal disc problem and in response to a question about why he wanted to view the image, he replied, *'I suppose it makes you feel a little bit more involved, a bit more interested, or a bit more involved in what's going on inside you, because it is your body. They would be sort of, kind of added extras. I could have come out and said, "Do you know what, they've showed me my back."'* Another respondent, F9, reported noticing a CT image of her kidneys on the monitor on her

doctor's desk. *'And I was sort of looking at it, and he went "Oh, that's not for you to see" and turned the screen, the computer screen [away]*'. Other respondents expressed concern about the added time it would take a doctor to show and explain the image. F22 felt that she would like to view images of her foot X-ray, but commented: *'It would be interesting yes, but I would think it's a time factor with lots of doctors having to stop and show people and explain everything.'* M24 concurred with respect to his lower back and pelvic image: '*If he had shown me the X-ray and I could have been a person that wanted to know every little detail of it and it could have been five, ten minutes explaining. But he's got a pressure of a queue outside waiting to come in.*'

Variation and trends in responses

Many participants (12/25) provided mixed responses about wanting to view their images, they wanted and appreciated the opportunity to view some images but not others. However, six participants were unambivalently in favour of viewing their images, whilst five did not ever wish to see them. Two participants had never seen their own images said they would have liked to have had the opportunity. No particular pattern emerged regarding preference and age or sex, but we found a trend with respect to anatomy: patients were more eager to view pictures of the skeleton, whereas soft tissue, especially abdominal organs, elicited a higher level of squeamishness and a reduced desire to view the image. F11 expressed huge enthusiasm about viewing x-rays of her spine, but added, *"I'm not saying I'd want to look at my own tummy, you know, but to look at an X-ray is brilliant'*—X-ray clearly connoting 'bones' to her. On the other hand our pilot interviewee, who was not recruited from primary care commented that bony X-rays serve as a reminder of mortality, in contrast to, for instance, antenatal ultrasound, which this respondent characterized as being '*completely different*', and '*about life*'. The desire or lack of desire to see one's own image was also linked for some with the seriousness of the ailment, or the danger of planned procedure. One participant, F23, discussed her examination for two ailments, one respiratory and one spinal. She feared the effects of her spinal problem more than her respiratory complaint and thus felt a greater desire to view for herself the image of her spine: *'…I wasn't worried about wheezing with my chest, I mean I know it could be serious, but I didn't think it was serious, but I was very worried about my spine because I was worried I would be like it for the rest of my life…'*.

Those participants who did not want to see the image felt that shared viewing the image was a waste of time, their own and that of the clinician. F20, who had undergone a neck X-ray for persistent pain, probably arthritic, felt only added frustration at viewing the image in the company of the specialist nurse-practitioner: *'…no, I mean if you don't know what you're looking at then it's not really very helpful is it'*. She said that had it been an image of her child she would have certainly wanted to see the image. F2, aged 81, consulted her GP for a problem with her spine, and also discussed an experience getting an X-ray for a foot injury. She felt that it might be *'interesting'* to see the image, but went on to say

'Well really you rely on the doctor don't you to advise and you just go along with that, so you're hoping that you're getting the right medication…. I mean they've been through all their learning haven't they, and degrees and such like, and they know better than I do, hopefully'.

F3, who felt strongly that she better understood and dealt with her pain from a fractured thumb because she had viewed the X-ray herself, also commented on the importance of trusting the doctor, who told her he was *'happy with the positioning of the fracture'*. The positioning as viewed on the X-ray did not look right to F3, who said *'…We were slightly confused … but you're trusting that the doctor knows what he's talking about, so that was really it, that was basically what he said…'*.

Discussion

Statement of principal findings

While clinicians order diagnostic imaging with the aim of adding to their information about a patient's complaint, the images themselves, and their production, do more than convey clinical data. For our research participants, adults aged 40 and above living in the south of England who had recently undergone diagnostic imaging, the static medical image occupies multiple positions: it enhances the patient's understanding of his or her complaint; it has the potential for emotional impact (positive and negative), and it affects the nature of the doctor-patient encounter. The three themes identified in the data highlight the symbolic meanings attaching to *the act of viewing* the images alongside the doctor: 1) greater comprehension of the illness or injury; 2) the emotional effect linked to viewing one's 'invisible body'; and 3) the influence of shared viewing of the image on the social dynamic of the medical consultation.

Strengths and weaknesses in relation to other studies, discussing important differences in results

Unlike other studies this investigation included both men and women, and took a patient-centred perspective focusing on the *process* of sharing images in a clinical consultation, rather than taking a medicalised, illness-centric stance enquiring about a particular ailment or procedure. Previous research has focused on diagnostic sub-groups and specific technologies (e.g. older women and bone densitometry [12]; pregnancy and ultrasound [16], mammography [17] and hysteroscopy [18]). All of these studies focus on women, but Cohn [19] explores neurological or psychiatric patients their understanding of their brain scans. Radstake [6] conducted what she calls 'endography' (i.e. an inner-looking take on 'ethnography') of patients undergoing real-time imaging in a Dutch hospital. A recurrent theme in this stream of literature is a sense of patients' discomfort with the imaging and with technology more generally. Reventlow et al. [13-15] working with Danish women in their 60s, noted that the highly technological nature of the investigation created in these *asymptomatic* women a sense of weakness and vulnerability. Griffiths et al. [17] explored women's perspectives on breast screening and mammogram, again finding that the visualisation technology imposes on women a devaluation of their own breast and body

awareness, 'separating the at-risk breast from embodied experience'. Our work, however, suggests that for some patients, in some situations, viewing their own images generates an almost opposite reaction, one of enhanced empowerment and of reassurance.

Van Dijck writes that 'patients often blindly trust the panoptic nature of the mechanical-clinical eye' ([20]: 8). In this study, we find otherwise; patients are neither blindly trusting nor entirely certain of the role of the image in clinical care, but are, like their doctors, finding their way through the information available to the best possible solution for them. Merleau-Ponty [21, 22] argues that perception is an embodied experience; that viewing images, in the case of one's self, becomes incorporated into the individual's sense of himself or herself. Cohn [23] reports that patients who chose to view images from their brain scans regarded the image as validating the sensation, the experience of mental illness. Where other forms of communication like reports and numerical data seem inaccessible, and perhaps inapplicable, the picture itself embodies and thus represents in a simple and, according to Cohn, 'autonomous' manner the mental illness and consequent suffering of that particular patient. In the present study, we have explored the role of the image in dealing with physical illness and injury.

Meaning of the study: possible explanations and implications for clinicians and policy makers

Our own previous research suggests that physician opinion about sharing images with the patients varies, and that the reasons for the decision 'to share or not to share' range from the logistic to the philosophical. Mol (2002) [5] writes that x-rays are done 'one body at a time'; our aim in this project has been to understand the perspectives of people whose bodies, one at a time, were investigated. We have described both positive and negative attitudes of these respondents toward seeing images of the interior body. These affective responses around the viewing of images, however, are not uncomplicated or unmitigated; more cognitive considerations also come into play, including which part of the body has been imaged, the nature of the ailment, and indeed the nature of the patient. Thus we cannot reach simple conclusions or make recommendations as to whether and when sharing images with patients promote a good outcome. For some patients the possibility of shared viewing of their of their own diagnostic images can be powerful and resonant experience in a variety of ways, including both better understanding of pain or other

sensations associated with diagnosis, and building a stronger alliance between doctor and patient. The nature and form of our data collection precludes giving a prescribed course of action regarding the showing or not showing images to particular patients, but we can say that an open and frank discussion of the possibility of such sharing is recommended. Further, we hope our work stimulates discussion amongst clinicians who will be increasingly faced with the opportunity to share visual evidence of health and disease with their patients.

Limitations of our study

Weaknesses include the limited age range of our population; all the adults were 40 years or older, with an average age of 65 years. It would be interesting to find out what a younger generation of patients thinks about the experience of viewing their own medical images. The data were collected retrospectively and are thus reliant on participants' recall. The number and characteristics of patients who were eligible for inclusion in this study but declined to participate are not available to us; this was a condition of the research ethics committee approval. Finally, the study was based in the UK where the availability of medical images in the clinical setting may differ from other countries. In the UK there is ready access to medical images during consultations in secondary care health settings, but it is not normal practice for general practitioners, working in the community, to access their patient's images, even if theoretically possible [3, 25]. In primary care generally it is only the written report of the image that is available and accessed in the consultation, however one of our recruiting general practices was unusual in having well established, direct access to a community based imaging facility (digital X-ray, DXA, and MRI).

Unanswered questions and future research

The clinical encounter takes place, usually, in a dyadic form; in the present study, we queried only one half of the dyad with respect to the experience of viewing or not viewing a particular image. These physician's own point of view, his or her own reasons for deciding 'to share or not to share', remain opaque to us, reported if at all only by conjecture or hearsay on the part of our research participants. An investigation involving both halves of the pair would be a very useful addition to the project and build on the work we have already done with radiologists and GPs about sharing images with their patients [3].

Another, almost completely unexplored component of medical imaging is the role of the technician or technologist: the individual who makes the image. Some of our participants reported significant encounters with the technician, both in terms of the experience of producing the image, and in terms of learning something of the results. Current guidelines regarding patient-technician interactions allow for leeway depending on the seniority and position of the technician. Further exploration of the technician's role regarding patient viewing of images would be of interest.

Details of contributors

Leslie Carlin (LC), Flis Henwood (FH) and Helen Smith (HS) developed the study idea and method. LC conducted the interviews. LC and HS read and coded the transcripts and interpreted the data. LC drafted the paper and HS and FH provided constructive feedback on all versions of the manuscript. Helen Smith is the guarantor of this paper.

Competing interest statement

All authors have completed the Unified Competing Interest form atwww.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

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Data sharing

No additional data available

Transparency declaration

Helen Smith (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained

Ethical approval

Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Reference number 09/H1102/105)

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Table 1: Characteristics of Interviewees (n=25)

Study ID (M=male; F=female)	Age at interview	Reason given by patient for imaging referral	Patient saw focal image	Has seen other medical images
F1	59	abdomen and chest x-rays (diverticulitis)	no	yes
F2	81	swollen knee x-ray	no	yes
F3	49	broken thumb x-ray	yes	yes
M4	83	swollen ankle x-ray	no	no
F5	44	head and neck MRI	yes	yes
F6	46	hip x-ray	yes	yes
M7	62	chest x-ray	no	yes
M8	76	hip x-ray	yes	yes
F9	49	chest x-ray (possible metastasis)	yes	yes
F10	72	chest/lung x-ray and CT fragility fracture leg, collarbone, x-ray and CT	yes	yes
F11	55	MRI	yes	yes
F12	71	spine; x-ray	no	yes
F13	41	back; x-ray and MRI	yes	yes
M14	49	chest x-ray	yes	yes
F15	74	back and torso x-ray	no	yes
M16	53	neck and shoulders; x-ray	no	yes
M17	83	spine; x-ray	yes	yes
M18	86	chest x-ray, MRI	no	yes
F19	65	mammogram	yes	yes
F20	48	neck x-ray	yes	yes
M21	74	hip x-xray	no	yes
F22	84	chest and foot x-ray	no	yes
F23	78	chest x-ray	yes	yes
M24	72	hip and spine x-ray and MRI	yes	yes
F25	75	arm x-ray	no	no

To see or not to see: a qualitative interview study of patients' views on their own diagnostic images

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Structured Abstract

Objectives - To ascertain what meaning individuals attach to perceiving images of their own interior body and how the images and their meanings affect the clinical consultation

Design - Face to face semi-structured interviews

Participants - 25 adult patients in southern England who within the preceding 12 months had been referred for diagnostic imaging

Setting - Community

Results - For patients, being shown their own X-rays, magnetic resonance images (MRIs) or computed tomography (CT) images creates a variety of effects: 1) a sense of better understanding of the diagnosis; 2) validation of their sensory and emotional response to the illness or injury; and 3) an alteration to the tenor and nature of the clinical encounter between patient and physician. In addition to meanings attached to these images, patients also impute meaning to the physician's decision *not* to share an image with them. The desire to see their image was greater in those patients with a skeletal injury; patients are less keen on viewing abdominal or other soft-tissue images.

Conclusions - Viewing images of one's interior, invisible body is powerful and resonant in a number of ways. The experience of not seeing, whether through the patient's or the physician's choice, is also fraught with meaning.

Article summary

Article focus

- There is a paucity of research involving diagnostic imaging in the context of clinical care rather than screening and preventative medicine. In addition, reports of men's perspective on viewing their own diagnostic images are mostly neglected. There has been no previous study exploring patients' reactions to seeing their own diagnostic images in consultation with their doctor.

Key messages

- The viewing their own static images create for patients a variety of effects: 1) a sense of better understanding of the diagnosis; 2) validation of their sensory and emotional response to the illness or injury; and 3) an alteration to the tenor and nature of the clinical encounter between patient and physician.
- In addition to meanings attached to these images, patients also impute meaning to the physician's decision *not* to share an image with them. The desire to see their image was greater in those patients with a skeletal injury; patients are less keen on viewing abdominal or other soft-tissue images.

Strengths and limitations

- Weaknesses include the limited age range of our population; all the adults were 40 years or older, with an average age of 65 years. It would be interesting to find out what a younger generation of patients thinks about the experience of viewing their own medical images.
- The data were collected retrospectively and are thus reliant on participants' recall. We queried only one half of the clinician-patient dyad with respect to the experience of viewing or not viewing a particular image. These physician's own point of view, his or her own reasons for deciding 'to share or not to share', remain opaque to us, reported if at all only by conjecture or hearsay on the part of our research participants.

Introduction

Medical imaging is used in health care for diagnosis, screening and for monitoring of both disease progression and treatment response. In England alone there were 38,805,537 imaging investigations[i] conducted in the NHS during 2010/11 [1]. The armamentarium of imaging techniques has vastly expanded since Roentgen's discovery of X-rays in 1895, and the 'authority of the image' [2] (page 20) has also, correspondingly, increased. In the present paper we begin to explore the meanings imputed to 'still' images when they are shared, or not shared, with patients, and so focus on computed tomography (CT) and magnetic resonance imaging (MRI) along with X-rays.

Development of digital imaging technology enables wider dissemination of images within medicine, and has changed the way these pictures are accessed and used clinically [3]. The literature on the role of medical imaging techniques concentrates on practitioners and institutions, and largely lacks the patient's viewpoint. A few exceptions are notable, including, the quite exceptional work by Blaxter, which explores her own experience as a patient looking for conflicting arguments about the ways in which medical technology, and in particular medical imaging, affect the management of illness and of doctor-patient relationships [4]. Blaxter describes how two opposing tropes have prevailed in describing the effects of medical technology on patients. In one the medical image might be seen as the oppressor of the patient, creating a situation in which 'technological representations hide the selves embedded in human bodies' (page 763). In this view, patients are rendered passive in the face of a technology understood only by the experts; in their turn, medical

experts' attitudes toward the pre-eminence and efficacy of technology is reinforced by their patients' submissiveness to the authority of that technology.

An alternate perspective is propounded by Mol [5] and others, who argue that rather than being alienated by high-tech medical procedures, patients as well as practitioners enlist their outputs both to manage their perceptions of themselves and their ailments, and to influence their treatment. Taking this vantage point, the body is not subdued by the image, nor is the patient rendered invisible by it, but rather the body is 'multiplied' to include 'the image as well as the reality' [4](page 764). '[T]he recalcitrant public is an absent presence in many of the "problems with the public" in the public understanding of science.' Blaxter concludes that the alienation experienced by patients stems not from the technology or the images, but from the system in which both technology and the medical profession are bound: creating a case of problematic 'social adaptation' (page 775). Apart from Blaxter's contribution, however, exploration of patients and their static images, in which they remain still and 'actively learn to be bodies' [6] and where the image production occurs remotely, is largely absent.

In addition, there has been an interesting thread in the medical anthropology and medical sociology literature exploring the role of women's experiences of particular procedures: screening mammography ([7]), antenatal foetal ultrasound [8 - 11], and bone densitometry [12-15]. There is however a paucity of research involving diagnostic imaging in the context of clinical care rather than screening and preventative medicine. In addition, reports of men's perspective on viewing their own diagnostic images are mostly neglected.

In a previous project, we queried general practitioners (GPs) and consultant radiologists about the impact of sharing medical images with patients during consultations, and about

the role of Picture Archiving and Communications (PACS) technology on the dissemination of diagnostic radiographic images beyond the hospital and into the arena of primary care [3]. In the current study, we shift the focus to the 'third leg' of the radiologist-clinician - patient tripod: the patient. Two central questions are addressed: i) what meanings do individuals attach to perceiving images of their own interior body? and ii) how do the images, and their meanings, affect the clinical consultation?

Methods

Participants and sampling

Twenty five patients from nine general practices in the south-east of England participated in this study (Table 1). A convenience sampling strategy was used, participants were recruited by eleven general practitioners who during the consultation enquired of the patients' willingness to participate in a semi-structured interview concerning their experiences of a recent referral from general practice for diagnostic imaging (X-ray, CT, or MRI). We focused on these modalities as they produce a static image that is viewed separately, as opposed to the dynamic procedure of ultrasonography (cf. Radstake [6]). The study inclusion criteria were: adult, fluent speaker of English, competent to consent, and had been referred to an outpatient imaging department within the past 12 months.

Interview procedure

Written consent was gained prior to beginning the interview, which was audio-recorded and professionally transcribed. All interviews were conducted by LC, an anthropologist by training. Topics included patients' experiences of undergoing an imaging procedure, their attitudes toward the viewing or not viewing the resulting images, and their beliefs and opinions concerning the place of such images in a clinical consultation. Descriptive (interview setting, participant behaviours) and reflective field notes were made during the interview process.

Analysis

Data were analysed following a qualitative descriptive method [16]. All transcripts were read and coded by two researchers (LC and HS), manually by both researchers, and using a computer-assisted qualitative data analysis program *(NVivo)* by one researcher (LC). Data were coded 'freehand' by creating as many new free nodes as seemed necessary, and then 'rolling up' nodes into hierarchies or trees. The freehand and the electronically-assisted coding produced very similar results.

Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Ref. no. 09/H1102/105).

Results

Twenty-five of 47 patients who expressed initial willingness to participate were interviewed; two potential participants changed their minds; the remainder were uncontactable, ineligible, or unavailable within the time frame of the project. Participants ranged from 41 to 86 years (mean age 65); nine (36%) were men. At the request of the ethics committee we did not count or collect information about the participants who declined the GPs invitation to participate. Most of the interviews were conducted in the participant's own home, but three individuals wished to be interviewed on university premises. Interviews ranged from 13 to 52 minutes, with a mean of 28 minutes.

While the patients were recruited on the basis of having undergone a recent diagnostic imaging procedure, sometimes other experiences of imaging also formed part of the discussion, for example earlier imaging experiences of themselves or others. Of the 25 participants, 14 (56%) reported having been shown the image that rendered them eligible for this study, and 23 (92%) spoke of how on some other occasion they had viewed images of themselves or of relatives (children, parents, spouses) (Table 1). In the results, to preserve anonymity, we use a convention of numbering participants, prefixed with 'M' to indicate a male and 'F' a female participant.

What the images mean to patients

Patients' opinions, wishes, and thoughts on images 'being shared with' varied, as did the meanings they took away from the experience—or the lack of the experience—of viewing their own interior. The themes that emerged from our coding formed three identifiable but interwoven strands, namely that being shown images 1) enhances understanding of the problem , 2) affects the emotional impact of diagnosis, and 3) changes the nature of the interaction with the physician during consultation.

Firstly, the patients who viewed their own images reported that doing so **enhanced their understanding** of their ailments. Seeing the image *informed*; it served as a visual aid in a basic pedagogical sense. In addition (one thread) the image also validated sensation—*'that's why it hurts like it does'* (participant F13). In either case, the result of seeing the image produced or enlarged knowledge *by* the patient *of* her own corpus, it linked body to mind;

several respondents commented that pain seemed easier to manage once they had seen its source 'for themselves'. F13 continues:

> *I think it was easy because then when he [physician] was talking about it and he could actually kind of point and see, so when someone is saying about the bottom disc missing from your spine you've got a vague idea of kind of where that is, but when you can actually look at it and he's pointing and showing you the different bits, and I think it actually helps you understand, it's not just some kind of airy fairy thing, it's actually there in front of you, and you can see it, and I think that's got to be a good thing.*

F3 concurred, saying *'…if I had any fractures in the future I would want to see the fracture because I think it helps you understand the pain, if that makes sense…He [the consultant] wasn't hugely informative but I think the x-ray picture said it all.'* In some cases, the expectation of knowledge emanating from the image was very high indeed, and possibly unrealistic in its reach: *'…If I was able to see the x-ray I might have been able to see something that, you know, where the pain is, and say to the doctor "Well that's where I'm getting this pain, that area there." And they might be able to either explode that image up and see if there is anything in that actual area'* (M16).

In a second theme, viewing the image had an ***emotional impact***, generally one of reassurance, and not necessarily reliant on greater comprehension of the medical facts of the case. For instance M8 described viewing an image of his lungs: *'I think this a modern sort of thing isn't it now? Where patients get to see x-rays. Good thing for settling you down and making you feel calmer I think, and being aware that there's nothing wrong. I mean most people haven't got any medical knowledge at all have they, to be quite honest. So they could have been sideways, upside down, I wouldn't have known the difference.'* participants often spoke of the importance of having trust or faith in the physician, whether GP or specialist, as being more important than seeing the image on which the doctor based his or her diagnosis or treatment recommendation: 'I've got faith in them, that their expertise is better than me looking at their pictures' (M8). Nonetheless, seeing the image for oneself

offered reassurance for *some* participants. F23, commenting on a recent spinal X-ray, remarked: *'I was relieved that I could see definitely having had it pointed out to me, what was wrong, and it wasn't anything that I could have avoided myself, that it was just the bones had come together, trapped the nerves, that was it, and I could see for myself what had happened.'* Other participants, however, felt added anxiety, as opposed to reassurance, about seeing an image that could convey bad news; for instance, a participant being investigated for possible lung cancer, F9, commented, *'I think it's a very grey area to want to see the X-ray if you don't know what you are looking for ….'.* M21 expressed a quite certain opposition to viewing his hip X-ray: *'…no, I don't think so, no, no, I don't want to look at it, I don't think so. I mean I don't want to see it to be honest… If it's bad I don't want to see it, you know, I can feel that it's not good, I know it's not good so I'll take that as evidence'*.

Finally, the third thematic strand in our analysis focuses on the impact of shared viewing of the medical image as ***changing the nature of the consultation with the physician***. Again, this theme comprises multiple threads. In one, we elucidate the manner in which the physical presence of the image serves as a focal point for both doctor and patient, changing the consultation dynamic. An example: F6, discussing her hip and lower spine X-ray, enthused, *'but to actually see it as a patient I think is invaluable really, I think it would be marvellous, and also in terms of mediating the relationship with your doctor because we're talking about a third thing, rather than it being… face to face…'*. This patient, an articulate woman familiar with medical argot and medical practitioners, finds comfort in having the image serve as a point of common interest, rather than she, as the patient, being the sole focus of the medical gaze. For other participants, the image almost becomes a third 'actor', more than a 'thing', within the room, exemplified by several quotes beginning *'The x-ray says*'; for instance, *'[T]he X-ray says arthritis'* (M24). The image, however, may attract the attention of the physician at the expense of the attention paid to the actual patient in the room, or, as in the case of participant M24, give the impression that the physician's opinion is at odds with the diagnosis 'made' by the image: *'I could tell he didn't quite agree with this X-ray. But he didn't say that. They don't say, "I don't agree with it."'*

The very decision made by the physician as to *whether* to show the image to the patient affects the way the patient understands the relationship between themselves and the doctor. Respondents with whom the doctor had deliberately shared an image felt more part

of the consultation, and sometimes of the treatment decisions. They also felt more respected and valued by their doctor, both because to share the image took more time than not to, and because the expectation of interest, even without comprehension, in the anatomical facts suggested that the doctor had a high opinion of the patient as a person. The act or fact of sharing implied respect and concern *'…because you feel they've taken the time to show you. You feel they care a lot'* (M24). F1, suffering from an abdominal complaint, commented:

> *I suppose it would be- yes, very sort of empowering in a kind of way if somebody had time to say "This is the X-ray, this is the thing we found, this is where the disintegration is but this bit's all right." I think yes it would be good, but I think it would so far exceed my expectations because of the lack of time that people have that it wouldn't even come into my head to think that it might be possible.*

M16 talks about his experience of seeing X-rays of his hip and shoulder, saying *'I think it brings you a little bit closer to the doctor and a bit more rapport with them. That's what I just feel.'* However, the effect of the clinician's decision about shared viewing of an image is perhaps conveyed most clearly by the comments of participants whose doctors chose *not* to share with them an image which the doctor was currently scrutinising. M24, speaking of his hip and spine X-ray, said *'[In]… fact I didn't ask because I don't think I'd know anything about it anyway. I wouldn't know anything on the X-ray. He could tell me, but I just felt – I didn't ask, so he wasn't going to show it'*. This respondent had caught a brief glimpse of the image on the doctor's monitor, which the doctor gazed at during the consultation, *'It's white, it's a light, it attracts your eye'*. This respondent disparaged his own intelligence when trying to explain why his doctor denied him a look at the image himself: *'I guess he has pressure, his other patients. And, but yes, he's very good. He would answer any questions I asked him. It's only our ignorance that we don't know what to ask…'*. From our interview, it is clear that this man had wit enough to ask thoughtful questions about his spinal disc problem and in response to a question about why he wanted to view the image, he replied, *'I suppose it makes you feel a little bit more involved, a bit more interested, or a bit more involved in what's going on inside you, because it is your body. They would be sort of, kind of added extras. I could have come out and said, "Do you know what, they've showed me my back."'* Another respondent, F9, reported noticing a CT image of her kidneys on the monitor on her

doctor's desk. *'And I was sort of looking at it, and he went "Oh, that's not for you to see" and turned the screen, the computer screen [away]*'. Other respondents expressed concern about the added time it would take a doctor to show and explain the image. F22 felt that she would like to view images of her foot X-ray, but commented: *'It would be interesting yes, but I would think it's a time factor with lots of doctors having to stop and show people and explain everything.'* M24 concurred with respect to his lower back and pelvic image: '*If he had shown me the X-ray and I could have been a person that wanted to know every little detail of it and it could have been five, ten minutes explaining. But he's got a pressure of a queue outside waiting to come in.*'

Variation and trends in responses

Many participants (12/25) provided mixed responses about wanting to view their images, they wanted and appreciated the opportunity to view some images but not others. However, six participants were unambivalently in favour of viewing their images, whilst five did not ever wish to see them. Two participants had never seen their own images said they would have liked to have had the opportunity. No particular pattern emerged regarding preference and age or sex, but we found a trend with respect to anatomy: patients were more eager to view pictures of the skeleton, whereas soft tissue, especially abdominal organs, elicited a higher level of squeamishness and a reduced desire to view the image. F11 expressed huge enthusiasm about viewing x-rays of her spine, but added, *"I'm not saying I'd want to look at my own tummy, you know, but to look at an X-ray is brilliant'*—X-ray clearly connoting 'bones' to her. On the other hand our pilot interviewee, who was not recruited from primary care commented that bony X-rays serve as a reminder of mortality, in contrast to, for instance, antenatal ultrasound, which this respondent characterized as being '*completely different*', and '*about life*'. The desire or lack of desire to see one's own image was also linked for some with the seriousness of the ailment, or the danger of planned procedure. One participant, F23, discussed her examination for two ailments, one respiratory and one spinal. She feared the effects of her spinal problem more than her respiratory complaint and thus felt a greater desire to view for herself the image of her spine: *'…I wasn't worried about wheezing with my chest, I mean I know it could be serious, but I didn't think it was serious, but I was very worried about my spine because I was worried I would be like it for the rest of my life…'*.

Those participants who did not want to see the image felt that shared viewing the image was a waste of time, their own and that of the clinician. F20, who had undergone a neck X-ray for persistent pain, probably arthritic, felt only added frustration at viewing the image in the company of the specialist nurse-practitioner: *' …no, I mean if you don't know what you're looking at then it's not really very helpful is it'*. She said that had it been an image of her child she would have certainly wanted to see the image. F2, aged 81, consulted her GP for a problem with her spine, and also discussed an experience getting an X-ray for a foot injury. She felt that it might be *'interesting'* to see the image, but went on to say

'Well really you rely on the doctor don't you to advise and you just go along with that, so you're hoping that you're getting the right medication…. I mean they've been through all their learning haven't they, and degrees and such like, and they know better than I do, hopefully'.

F3, who felt strongly that she better understood and dealt with her pain from a fractured thumb because she had viewed the X-ray herself, also commented on the importance of trusting the doctor, who told her he was *'happy with the positioning of the fracture'*. The positioning as viewed on the X-ray did not look right to F3, who said *'…We were slightly confused … but you're trusting that the doctor knows what he's talking about, so that was really it, that was basically what he said…'*.

Discussion

Statement of principal findings

While clinicians order diagnostic imaging with the aim of adding to their information about a patient's complaint, the images themselves, and their production, do more than convey clinical data. For our research participants, adults aged 40 and above living in the south of England who had recently undergone diagnostic imaging, the static medical image occupies multiple positions: it enhances the patient's understanding of his or her complaint; it has the potential for emotional impact (positive and negative), and it affects the nature of the doctor-patient encounter. The three themes identified in the data highlight the symbolic meanings attaching to *the act of viewing* the images alongside the doctor: 1) greater comprehension of the illness or injury; 2) the emotional effect linked to viewing one's 'invisible body'; and 3) the influence of shared viewing of the image on the social dynamic of the medical consultation.

Strengths and weaknesses in relation to other studies, discussing important differences in results

Unlike other studies this investigation included both men and women, and took a patient-centred perspective focusing on the *process* of sharing images in a clinical consultation, rather than taking a medicalised, illness-centric stance enquiring about a particular ailment or procedure. Previous research has focused on diagnostic sub-groups and specific technologies (e.g. older women and bone densitometry [12]; pregnancy and ultrasound [16], mammography [17] and hysteroscopy [18]). All of these studies focus on women, but Cohn [19] explores neurological or psychiatric patients their understanding of their brain scans. Radstake [6] conducted what she calls 'endography' (i.e. an inner-looking take on 'ethnography') of patients undergoing real-time imaging in a Dutch hospital. A recurrent theme in this stream of literature is a sense of patients' discomfort with the imaging and with technology more generally. Reventlow et al. [13-15] working with Danish women in their 60s, noted that the highly technological nature of the investigation created in these *asymptomatic* women a sense of weakness and vulnerability. Griffiths et al. [17] explored women's perspectives on breast screening and mammogram, again finding that the visualisation technology imposes on women a devaluation of their own breast and body

awareness, 'separating the at-risk breast from embodied experience'. Our work, however, suggests that for some patients, in some situations, viewing their own images generates an almost opposite reaction, one of enhanced empowerment and of reassurance.

Van Dijck writes that 'patients often blindly trust the panoptic nature of the mechanical-clinical eye' ([20]: 8). In this study, we find otherwise; patients are neither blindly trusting nor entirely certain of the role of the image in clinical care, but are, like their doctors, finding their way through the information available to the best possible solution for them. Merleau-Ponty [21, 22] argues that perception is an embodied experience; that viewing images, in the case of one's self, becomes incorporated into the individual's sense of himself or herself. Cohn [23] reports that patients who chose to view images from their brain scans regarded the image as validating the sensation, the experience of mental illness. Where other forms of communication like reports and numerical data seem inaccessible, and perhaps inapplicable, the picture itself embodies and thus represents in a simple and, according to Cohn, 'autonomous' manner the mental illness and consequent suffering of that particular patient. In the present study, we have explored the role of the image in dealing with physical illness and injury.

Meaning of the study: possible explanations and implications for clinicians and policy makers

Our own previous research suggests that physician opinion about sharing images with the patients varies, and that the reasons for the decision 'to share or not to share' range from the logistic to the philosophical. Mol (2002) [5] writes that x-rays are done 'one body at a time'; our aim in this project has been to understand the perspectives of people whose bodies, one at a time, were investigated. We have described both positive and negative attitudes of these respondents toward seeing images of the interior body. These affective responses around the viewing of images, however, are not uncomplicated or unmitigated; more cognitive considerations also come into play, including which part of the body has been imaged, the nature of the ailment, and indeed the nature of the patient. Thus we cannot reach simple conclusions or make recommendations as to whether and when sharing images with patients promote a good outcome. For some patients the possibility of shared viewing of their of their own diagnostic images can be powerful and resonant experience in a variety of ways, including both better understanding of pain or other

sensations associated with diagnosis, and building a stronger alliance between doctor and patient. The nature and form of our data collection precludes giving a prescribed course of action regarding the showing or not showing images to particular patients, but we can say that an open and frank discussion of the possibility of such sharing is recommended. Further, we hope our work stimulates discussion amongst clinicians who will be increasingly faced with the opportunity to share visual evidence of health and disease with their patients.

Limitations of our study

Weaknesses include the limited age range of our population; all the adults were 40 years or older, with an average age of 65 years. It would be interesting to find out what a younger generation of patients thinks about the experience of viewing their own medical images. The data were collected retrospectively and are thus reliant on participants' recall. The number and characteristics of patients who were eligible for inclusion in this study but declined to participate are not available to us; this was a condition of the research ethics committee approval. Finally, the study was based in the UK where the availability of medical images in the clinical setting may differ from other countries. In the UK there is ready access to medical images during consultations in secondary care health settings, but it is not normal practice for general practitioners, working in the community, to access their patient's images, even if theoretically possible [3, 25]. In primary care generally it is only the written report of the image that is available and accessed in the consultation, however one of our recruiting general practices was unusual in having well established, direct access to a community based imaging facility (digital X-ray, DXA, and MRI).

Unanswered questions and future research

The clinical encounter takes place, usually, in a dyadic form; in the present study, we queried only one half of the dyad with respect to the experience of viewing or not viewing a particular image. These physician's own point of view, his or her own reasons for deciding 'to share or not to share', remain opaque to us, reported if at all only by conjecture or hearsay on the part of our research participants. An investigation involving both halves of the pair would be a very useful addition to the project and build on the work we have already done with radiologists and GPs about sharing images with their patients [3].

Another, almost completely unexplored component of medical imaging is the role of the technician or technologist: the individual who makes the image. Some of our participants reported significant encounters with the technician, both in terms of the experience of producing the image, and in terms of learning something of the results. Current guidelines regarding patient-technician interactions allow for leeway depending on the seniority and position of the technician. Further exploration of the technician's role regarding patient viewing of images would be of interest.

Details of contributors

Leslie Carlin (LC), Flis Henwood (FH) and Helen Smith (HS) developed the study idea and method. LC conducted the interviews. LC and HS read and coded the transcripts and interpreted the data. LC drafted the paper and HS and FH provided constructive feedback on all versions of the manuscript. Helen Smith is the guarantor of this paper.

Competing interest statement

All authors have completed the Unified Competing Interest form atwww.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Details of funding

There was no external funding for this project

Data sharing

No additional data available

Transparency declaration

Helen Smith (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained

Ethical approval

Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Reference number 09/H1102/105)

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Table 1: Characteristics of Interviewees (n=25)

Study ID (M=male; F=female)	Age at interview	Reason given by patient for imaging referral	Patient saw focal image	Has seen other medical images
F1	59	abdomen and chest x-rays (diverticulitis)	no	yes
F2	81	swollen knee x-ray	no	yes
F3	49	broken thumb x-ray	yes	yes
M4	83	swollen ankle x-ray	no	no
F5	44	head and neck MRI	yes	yes
F6	46	hip x-ray	yes	yes
M7	62	chest x-ray	no	yes
M8	76	hip x-ray	yes	yes
F9	49	chest x-ray (possible metastasis)	yes	yes
F10	72	chest/lung x-ray and CT fragility fracture leg, collarbone, x-ray and CT	yes	yes
F11	55	MRI	yes	yes
F12	71	spine; x-ray	no	yes
F13	41	back; x-ray and MRI	yes	yes
M14	49	chest x-ray	yes	yes
F15	74	back and torso x-ray	no	yes
M16	53	neck and shoulders; x-ray	no	yes
M17	83	spine; x-ray	yes	yes
M18	86	chest x-ray, MRI	no	yes
F19	65	mammogram	yes	yes
F20	48	neck x-ray	yes	yes
M21	74	hip x-xray	no	yes
F22	84	chest and foot x-ray	no	yes
F23	78	chest x-ray	yes	yes
M24	72	hip and spine x-ray and MRI	yes	yes
F25	75	arm x-ray	no	no

Research Checklist

This checklist includes the original protocol and a COREC check list

Provisional research plan: patient perspective of viewing images (PACS and patients = PaP)

Principal and secondary research questions:

1. 'How does viewing their own radiograph or other scan as part of a clinical consultation affect patients?'

2. Secondary objectives include 1) exploration of the valence of any effect (positive or negative) of having viewed the image during a consultation; 2) investigation of constructive 'after effects' of viewing such an image, e.g. around comprehension of a diagnosis or compliance with treatment.

Summary of study:

This research project is designed to explore the impact on patients of viewing their own radiologic images: mainly x-rays, but also MRIs and CT scans. There is a dearth of information available about how sharing x-ray and other radiologic images with patients affects the clinical consultation. Currently in the UK, a GP may refer a patient to radiology services for investigation of a problem; a radiologist then views the image and sends a report back to the referring physician for discussion of diagnosis and any treatment. Increasingly with the advent of Picture Archiving and Communications Systems (PACS) within the NHS, it is feasible that the image will accompany the report, and the GP will be able to share both information and image with his or her patients. We wish to investigate the impact of 'sharing images with patients' (SIP) on the patient and more generally on the patient journey. There is a large literature concerning the use of digital radiologic images for diagnosis and teaching within medicine, and for remote medical care, but relatively little on the impact of sharing such images with patients themselves. What research exists, has been conducted with regard to specific health issues in women at particular life stages, e.g. bone densitometry scans, mammography, or fetal ultrasonography. Research on health literacy has reviewed the use of pictorial modes of communication and found them to be of great use in some circumstances, so it is reasonable to think that images of their own bodies will be effective in communicating with patients. Our previous research investigated consultant radiologists' and GPs' views on PACS in a previous study; our current aim is thus to explore the third 'leg' of the 'tripod': patients' perspectives on a) viewing their x-rays, b) the role of x-rays in the 'patient journey', and c) experience of x-ray services.

Summary of main issues:

The main ethical issues revolve around a) being sensitive to participants' own concerns that are distinct from our research interests and b) maintaining privacy and confidentiality. Point

Research Checklist

(a) will be addressed by targeting patients who are unlikely to be in situations that arouse particular alarm (i.e. in non-acute and non-life-threatening condition). To maintain privacy and confidentiality (point b), utmost care will be taken to conduct interviews in private, to use coding to protect identities, and to destroy and discard any personal or identifying information pertaining to individuals who may be contacted but decline to participate.

Scientific justification:

With film x-rays, the typical route for a patient referred from primary care involved a picture being viewed by a radiologist or other specialist, followed by a report transmitted to the GP, who fed back to the patient based on a written report. With the advent of PACS and filmless technology, the roll-out of PACS to primary care settings is in process. Once this is in place, it is envisioned that both report and image will be transmitted to the primary care physician. How will this affect the consultation? In what situations is the visual imagery useful, or perhaps detrimental? In our previous research, we explored the attitudes and beliefs of GPs and of consultant radiologists toward this 'sharing of images with patients' (SIP); our analysis suggests that both benefits and drawbacks accrue to the general practitioner from such a system. To our knowledge, no exploration has as yet been conducted about the impact of viewing their own radiographic image on patients within a consultation; the current project is designed to remedy that omission.

The proposed project is an outgrowth of previous research which was approved and funded by the Brighton and Sussex Medical School [details], results of which have been presented at professional conferences and are currently under review for a scientific journal. The research questions to be addressed here are of a developmental nature and are intended to lead to an application for a grant in the near future.

Design and methods:

We intend to recruit patients referred to the imaging service from primary care at the outpatient clinic, either polyclinic or hospital outpatient facility. Patients will be asked either while waiting for their appointment, or just afterward, whether they would consider talking with a researcher after receiving their results, about their experience of undergoing an x-ray [or other procedure] and about the subsequent consultation. An information leaflet with contact details will be provided, and it will be made clear that opting out at any time is possible.

Participants in the study will be recruited from those patients referred by GPs for outpatient x-ray or scan procedures. A small number (yet to be determined) of GP surgeries will be invited to cooperate in this developmental phase, and cooperating GPs will ask patients who meet the inclusion criteria whether a researcher may contact them by phone, post, or email after their imaging procedure. If the patient agrees, a researcher (LC) will contact them by the agreed method some time after their procedure to arrange an interview. A consent form will be sent to them prior to the arranged meeting, and the interview will proceed only after the consent form is signed. Thus consent will be obtained in a two-stage process: first, consent for the researcher to contact the participant at an appropriate date, and second, consent to being interviewed.

Research Checklist

We will request contact details for those who agree to participate, and will contact them by their preferred route (phone, post, or email) about a week after the procedure, to catch them as soon after any follow-up consultation as possible.

We anticipate a developmental phase to the study in which semi-structured interviews with the first 3 or 4 patients will frame a series of questions to be consistently included in interviews with the formal sample of approximately 25 patients.

In our previous project, we found that interviews with just over 30 individuals in two professional groups (GPs and radiologists) gave us data saturation; further data collection was unlikely to provide new information. Since the aim of this research is to develop a broad outline of the experience of viewing medical images, we feel that a similar point of data saturation will be reached with 25-30 participants. Reventlow et al. (2006) describe a study of women learning their results of a bone density scan by viewing charts and images; in that project, 16 respondents were included. Because we anticipate interviewing patients some of whom have and some who have not viewed their own radiologic images, we are aiming for a higher total number.

Interviews are anticipated to last approximately 30 minutes; they will be conducted by Dr. Leslie Carlin; location will be flexible for convenience of participants (most likely to be face-to-face in a GP surgery if room available, alternatively, at the university, or in patient's home, or by telephone.

Initial questions we wish to include:

* Introduce our research as being about the use of x-rays or scans in consultations
* Name, age, gender, birthplace [if non-local, how long living in Sussex- see below]
* For what complaint were you referred to the hospital/clinic for an x-ray/scan?
* What sort of information were you given by the technician who took the x-ray/scan?
* How long was the wait if any between referral, procedure, and learning results?
* If you met with someone to discuss your results, who did you meet, and where?
* How was that information presented [probe for clarity, sympathy, patience]?
* Did [whoever] show you the x-ray/scan during your consultation? if yes:
  * Did you think it was a good thing to be able to see the picture of your [blank]? If yes, why? If no, why not?
  * Did [whoever] use the picture in his/her explanation to you about your results? If yes, in what way was the picture useful?
* [if relevant, may follow up with questions about similar procedure in place of origin]

The data will be transcribed and all transcripts read by one researcher (LC). The transcripts will be entered into NVivo, a computer-assisted qualitative data analysis program, which facilitates creative consideration and evaluation of verbal data in a variety of ways, and also serves as a tool for developing draft reports. The theoretical perspective will make sensible use of a grounded theory approach (taking the data as they come, without preconceptions) but will also take on board Merleau-Ponty's (1962) argument that perception is an embodied experience, i.e. that viewing images, in this case of one's self, becomes incorporated into the individual's sense of himself or herself.

Involvement of patients and service users:

Research Checklist

The set of interview questions will be trialled on the first few respondents and the interview schedule reviewed modified if necessary. All participants (who are both patients and service users) will be essential in managing and undertaking the research, as only their cooperation will drive it forward. As this is a qualitative study, analysis relies on the patients responding in a thoughtful and analytic manner to our proposed questions. Finally, all participants will be offered the opportunity to receive their own lay account of findings in writing, or to meet with the researchers in person.

Inclusion/exclusion criteria:

Inclusion: adult patients referred by their GP for outpatient X-ray. Exclusion: patients who cannot give own consent (some learning disabled or psychiatric patients); patients deemed by the referring GP as vulnerable; patients whose referral is deemed by the referring GP to be for reasons that are likely to be traumatic.

Risks and risk management:

Potential risks and burdens to respondents include the intrusion of contact with a researcher, and possible distress at re-living an uncomfortable experience. We will not encourage people to participate in the project unless they are freely willing, and will clarify that they may withdraw at any point, even mid-interview. The interviewer is an anthropologist experienced at conducting face-to-face research who will use her own judgement to as well to ascertain that participants are comfortable being part of the project.

Interviews will be conducted in a location agreed by both participant and researcher, designed to be comfortable for the participant. Attention to privacy will be foremost although we remain sensitive to the fact that for some respondents, company might be desirable. The interviewer (Dr. Leslie Carlin) is an anthropologist and is experienced at discussing unusual topics with people. The interview is semi-structured, so that respondents will be able to guide the discussion in a direction that is comfortable to them- there are no questions that they have to answer. Privacy and confidentiality will be maintained throughout data collection, analysis, and reporting.

Risks to researchers are minuscule, and are limited to personal security in certain interviewing situations. The risk can be minimised by utilising an automated security reporting system (CRYSIS). Common sense will prevail, and if the interviewer feels threatened or even uncertain, she will abort the meeting.

Confidentiality and data protection:

Participants will be pseudonymised and a coded key kept electronically in a password-protected location. Any paper notes that include personal data will be stored in a locked filing cabinet in a locked office in a secure building on the university campus.

Information will be stored on password-protected computer accounts held and secured by the University of Brighton. Any work on this information done from the researcher's home can also be done via a secure network directly to the the university system, so that no personal data relating to participants need be stored on home computer or laptop. Paper-based information will be stored in a locked filing cabinet in a locked (when unoccupied) office, in a secure building on the university campus.

Research Checklist

It is likely that personal and potentially identifying information will be stored on and transferred between work (university) and home computers, via email or other network. Direct quotations may be used in reports and publications. Address or phone numbers will most likely be used for contacting participants and for making arrangements to meet. The interviews will be audio-taped for later transcription.

Paper data will be stored in locked filing cabinets; electronic files in a password-protected account belonging to Prof. Helen Smith, on the university's mainframe computer. Data will be stored for up to 10 years, as it is hoped that this project will generate a further program of work.

Research Checklist

Transparency declaration Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

Table 1
Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		

Table 1

Research Checklist

No	Item	Guide questions/description
		interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned No	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking No	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

Research Checklist

No	Item	Guide questions/description
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? *e.g. face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? *e.g. home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the

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To see or not to see: a qualitative interview study of patients' views on their own diagnostic images

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To see or not to see: a qualitative interview study of patients' views on their own diagnostic images

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Structured Abstract

Objectives - To ascertain what meaning individuals attach to perceiving images of their own interior body and how the images and their meanings affect the clinical consultation

Design - Face to face semi-structured interviews

Participants - 25 adult patients in southern England who within the preceding 12 months had been referred for diagnostic imaging

Setting - Community

Results - For patients, being shown their own X-rays, magnetic resonance images (MRIs) or computed tomography (CT) images creates a variety of effects: 1) a sense of better understanding of the diagnosis; 2) validation of their sensory and emotional response to the illness or injury; and 3) an alteration to the tenor and nature of the clinical encounter between patient and physician. In addition to meanings attached to these images, patients also impute meaning to the physician's decision *not* to share an image with them. The desire to see their image was greater in those patients with a skeletal injury; patients are less keen on viewing abdominal or other soft-tissue images.

Conclusions - Viewing images of one's interior, invisible body is powerful and resonant in a number of ways. The experience of not seeing, whether through the patient's or the physician's choice, is also fraught with meaning.

Article summary

Article focus

- There is a paucity of research involving diagnostic imaging in the context of clinical care rather than screening and preventative medicine. In addition, reports of men's perspective on viewing their own diagnostic images are mostly neglected. There has been no previous study exploring patients' reactions to seeing their own diagnostic images in consultation with their doctor.

Key messages

- The viewing their own static images create for patients a variety of effects: 1) a sense of better understanding of the diagnosis; 2) validation of their sensory and emotional response to the illness or injury; and 3) an alteration to the tenor and nature of the clinical encounter between patient and physician.
- In addition to meanings attached to these images, patients also impute meaning to the physician's decision *not* to share an image with them. The desire to see their image was greater in those patients with a skeletal injury; patients are less keen on viewing abdominal or other soft-tissue images.

Strengths and limitations

- Weaknesses include the limited age range of our population; all the adults were 40 years or older, with an average age of 65 years. It would be interesting to find out what a younger generation of patients thinks about the experience of viewing their own medical images.
- The data were collected retrospectively and are thus reliant on participants' recall. We queried only one half of the clinician-patient dyad with respect to the experience of viewing or not viewing a particular image. These physician's own point of view, his or her own reasons for deciding 'to share or not to share', remain opaque to us, reported if at all only by conjecture or hearsay on the part of our research participants.

Introduction

Medical imaging is used in health care for diagnosis, screening and for monitoring of both disease progression and treatment response. In England alone there were 38,805,537 imaging investigations conducted in the NHS during 2010/11 [1]. The armamentarium of imaging techniques has vastly expanded since Roentgen's discovery of X-rays in 1895, and the 'authority of the image' [2] has also, correspondingly, increased. In the present paper we begin to explore the meanings imputed to 'still' images when they are shared, or not shared, with patients, and so focus on computed tomography (CT) and magnetic resonance imaging (MRI) along with X-rays.

Development of digital imaging technology enables wider dissemination of images within medicine, and has changed the way these pictures are accessed and used clinically [3]. The literature on the role of medical imaging techniques concentrates on practitioners and institutions, and largely lacks the patient's viewpoint. A notable exception is the work by Blaxter, which explores her own experience as a patient looking for conflicting arguments about the ways in which medical technology, and in particular medical imaging, affect the management of illness and of doctor-patient relationships [4]. Blaxter describes how two opposing tropes have prevailed in describing the effects of medical technology on patients. In one the medical image might be seen as the oppressor of the patient, creating a situation in which 'technological representations hide the selves embedded in human bodies'. In this view, patients are rendered passive in the face of a technology understood only by the experts; in their turn, medical experts' attitudes toward the pre-eminence and efficacy of

technology is reinforced by their patients' submissiveness to the authority of that technology.

An alternate perspective, propounded by Mol [5] and others, argue that rather than being alienated by high-tech medical procedures, patients, as well as practitioners, enlist their outputs both to manage their perceptions of themselves and their ailments, and to influence their treatment. Taking this vantage point, the body is not subdued by the image, nor is the patient rendered invisible by it, but rather the body is 'multiplied' to include 'the image as well as the reality' [4] Although other work exploring patients and their static images is largely absent [6] there has been an interesting thread in the medical anthropology and medical sociology literature exploring the role of women's experiences of particular screening and preventative medicine procedures: screening mammography ([7]), antenatal foetal ultrasound [8 - 11], and bone densitometry [12-15]. Unfortunately this research has not extended into the context of general clinical care and has neglected the perspectives of men. In a previous project, we queried general practitioners (GPs) and consultant radiologists about the impact of sharing medical images with patients during consultations, and about the role of Picture Archiving and Communications (PACS) technology on the dissemination of diagnostic radiographic images beyond the hospital and into the arena of primary care [3]. In the current study, we shift the focus to the 'third leg' of the radiologist-clinician -patient tripod: the patient. Two central questions are addressed: i) what meanings do individuals attach to perceiving images of their own interior body? and ii) how do the images, and their meanings, affect the clinical consultation?

Methods

Participants and sampling

Twenty five patients from nine general practices in the south-east of England participated in this study (Table 1). A convenience sampling strategy was used, participants were recruited by eleven general practitioners who during the consultation enquired of the patients' willingness to participate in a semi-structured interview concerning their experiences of a recent referral from general practice for diagnostic imaging (X-ray, CT, or MRI). We focused on these modalities as they produce a static image that is viewed separately, as opposed to the dynamic procedure of ultrasonography (cf. Radstake [6]). The study inclusion criteria were: adult, fluent speaker of English, competent to consent, and had been referred to an outpatient imaging department within the past 12 months.

Interview procedure

Written consent was gained prior to beginning the interview, which was audio-recorded and professionally transcribed. All interviews were conducted by LC, an anthropologist by training. Topics included patients' experiences of undergoing an imaging procedure, their attitudes toward the viewing or not viewing the resulting images, and their beliefs and opinions concerning the place of such images in a clinical consultation. Descriptive (interview setting, participant behaviours) and reflective field notes were made during the interview process.

Analysis

Data were analysed following a qualitative descriptive method [16]. All transcripts were read and coded by two researchers (LC and HS), manually by both researchers, and using a computer-assisted qualitative data analysis program *(NVivo)* by one researcher (LC). Data were coded 'freehand' by creating as many new free nodes as seemed necessary, and then 'rolling up' nodes into hierarchies or trees. The freehand and the electronically-assisted coding produced very similar results.

Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Ref. no. 09/H1102/105).

Results

Twenty-five of 47 patients who expressed initial willingness to participate were interviewed; two potential participants changed their minds; the remainder were uncontactable, ineligible, or unavailable within the time frame of the project. Participants ranged from 41 to 86 years (mean age 65); nine (36%) were men. At the request of the ethics committee we did not count or collect information about the participants who declined the GPs invitation to participate. Most of the interviews were conducted in the participant's own home, but three individuals wished to be interviewed on university premises. Interviews ranged from 13 to 52 minutes, with a mean of 28 minutes.

While the patients were recruited on the basis of having undergone a recent diagnostic imaging procedure, sometimes other experiences of imaging also formed part of the discussion, for example earlier imaging experiences of themselves or others. Of the 25 participants, 14 (56%) reported having been shown the image that rendered them eligible for this study, and 23 (92%) spoke of how on some other occasion they had viewed images of themselves or of relatives (children, parents, spouses) (Table 1). In the results, to preserve anonymity, we use a convention of numbering participants, prefixed with 'M' to indicate a male and 'F' a female participant.

What the images mean to patients

Patients' opinions, wishes, and thoughts on images 'being shared with' varied, as did the meanings they took away from the experience—or the lack of the experience—of viewing their own interior. The themes that emerged from our coding formed three identifiable but interwoven strands, namely that being shown images 1) enhances understanding of the problem , 2) affects the emotional impact of diagnosis, and 3) changes the nature of the interaction with the physician during consultation.

Firstly, the patients who viewed their own images reported that doing so **enhanced their understanding** of their ailments. Seeing the image *informed*; it served as a visual aid in a basic pedagogical sense. In addition (one thread) the image also validated sensation—*'that's why it hurts like it does'* (participant F13). In either case, the result of seeing the image produced or enlarged knowledge *by* the patient *of* her own corpus, it linked body to mind;

several respondents commented that pain seemed easier to manage once they had seen its source 'for themselves'. F13 continues:

> *I think it was easy because then when he [physician] was talking about it and he could actually kind of point and see, so when someone is saying about the bottom disc missing from your spine you've got a vague idea of kind of where that is, but when you can actually look at it and he's pointing and showing you the different bits, and I think it actually helps you understand, it's not just some kind of airy fairy thing, it's actually there in front of you, and you can see it, and I think that's got to be a good thing.*

F3 concurred, saying *'…if I had any fractures in the future I would want to see the fracture because I think it helps you understand the pain, if that makes sense…He [the consultant] wasn't hugely informative but I think the x-ray picture said it all.'* In some cases, the expectation of knowledge emanating from the image was very high indeed, and possibly unrealistic in its reach: *'…If I was able to see the x-ray I might have been able to see something that, you know, where the pain is, and say to the doctor "Well that's where I'm getting this pain, that area there." And they might be able to either explode that image up and see if there is anything in that actual area'* (M16).

In a second theme, viewing the image had an ***emotional impact***, generally one of reassurance, and not necessarily reliant on greater comprehension of the medical facts of the case. For instance M8 described viewing an image of his lungs: *'I think this a modern sort of thing isn't it now? Where patients get to see x-rays. Good thing for settling you down and making you feel calmer I think, and being aware that there's nothing wrong. I mean most people haven't got any medical knowledge at all have they, to be quite honest. So they could have been sideways, upside down, I wouldn't have known the difference.'* participants often spoke of the importance of having trust or faith in the physician, whether GP or specialist, as being more important than seeing the image on which the doctor based his or her diagnosis or treatment recommendation: 'I've got faith in them, that their expertise is better than me looking at their pictures' (M8). Nonetheless, seeing the image for oneself

offered reassurance for *some* participants. F23, commenting on a recent spinal X-ray, remarked: *'I was relieved that I could see definitely having had it pointed out to me, what was wrong, and it wasn't anything that I could have avoided myself, that it was just the bones had come together, trapped the nerves, that was it, and I could see for myself what had happened.'* Other participants, however, felt added anxiety, as opposed to reassurance, about seeing an image that could convey bad news; for instance, a participant being investigated for possible lung cancer, F9, commented, *'I think it's a very grey area to want to see the X-ray if you don't know what you are looking for ….'.* M21 expressed a quite certain opposition to viewing his hip X-ray: *'…no, I don't think so, no, no, I don't want to look at it, I don't think so. I mean I don't want to see it to be honest… If it's bad I don't want to see it, you know, I can feel that it's not good, I know it's not good so I'll take that as evidence'*.

Finally, the third thematic strand in our analysis focuses on the impact of shared viewing of the medical image as ***changing the nature of the consultation with the physician***. Again, this theme comprises multiple threads. In one, we elucidate the manner in which the physical presence of the image serves as a focal point for both doctor and patient, changing the consultation dynamic. An example: F6, discussing her hip and lower spine X-ray, enthused, *'but to actually see it as a patient I think is invaluable really, I think it would be marvellous, and also in terms of mediating the relationship with your doctor because we're talking about a third thing, rather than it being… face to face…'*. This patient, an articulate woman familiar with medical argot and medical practitioners, finds comfort in having the image serve as a point of common interest, rather than she, as the patient, being the sole focus of the medical gaze. For other participants, the image almost becomes a third 'actor', more than a 'thing', within the room, exemplified by several quotes beginning *'The x-ray says*'; for instance, *'[T]he X-ray says arthritis'* (M24). The image, however, may attract the attention of the physician at the expense of the attention paid to the actual patient in the room, or, as in the case of participant M24, give the impression that the physician's opinion is at odds with the diagnosis 'made' by the image: *'I could tell he didn't quite agree with this X-ray. But he didn't say that. They don't say, "I don't agree with it."'*

The very decision made by the physician as to *whether* to show the image to the patient affects the way the patient understands the relationship between themselves and the doctor. Respondents with whom the doctor had deliberately shared an image felt more part

of the consultation, and sometimes of the treatment decisions. They also felt more respected and valued by their doctor, both because to share the image took more time than not to, and because the expectation of interest, even without comprehension, in the anatomical facts suggested that the doctor had a high opinion of the patient as a person. The act or fact of sharing implied respect and concern *'…because you feel they've taken the time to show you. You feel they care a lot'* (M24). F1, suffering from an abdominal complaint, commented:

> *I suppose it would be- yes, very sort of empowering in a kind of way if somebody had time to say "This is the X-ray, this is the thing we found, this is where the disintegration is but this bit's all right." I think yes it would be good, but I think it would so far exceed my expectations because of the lack of time that people have that it wouldn't even come into my head to think that it might be possible.*

M16 talks about his experience of seeing X-rays of his hip and shoulder, saying *'I think it brings you a little bit closer to the doctor and a bit more rapport with them. That's what I just feel.'* However, the effect of the clinician's decision about shared viewing of an image is perhaps conveyed most clearly by the comments of participants whose doctors chose *not* to share with them an image which the doctor was currently scrutinising. M24, speaking of his hip and spine X-ray, said *'[In]… fact I didn't ask because I don't think I'd know anything about it anyway. I wouldn't know anything on the X-ray. He could tell me, but I just felt – I didn't ask, so he wasn't going to show it'*. This respondent had caught a brief glimpse of the image on the doctor's monitor, which the doctor gazed at during the consultation, *'It's white, it's a light, it attracts your eye'*. This respondent disparaged his own intelligence when trying to explain why his doctor denied him a look at the image himself: *'I guess he has pressure, his other patients. And, but yes, he's very good. He would answer any questions I asked him. It's only our ignorance that we don't know what to ask…'*. From our interview, it is clear that this man had wit enough to ask thoughtful questions about his spinal disc problem and in response to a question about why he wanted to view the image, he replied, *'I suppose it makes you feel a little bit more involved, a bit more interested, or a bit more involved in what's going on inside you, because it is your body. They would be sort of, kind of added extras. I could have come out and said, "Do you know what, they've showed me my back."'* Another respondent, F9, reported noticing a CT image of her kidneys on the monitor on her

doctor's desk. *'And I was sort of looking at it, and he went "Oh, that's not for you to see" and turned the screen, the computer screen [away]*'. Other respondents expressed concern about the added time it would take a doctor to show and explain the image. F22 felt that she would like to view images of her foot X-ray, but commented: *'It would be interesting yes, but I would think it's a time factor with lots of doctors having to stop and show people and explain everything.'* M24 concurred with respect to his lower back and pelvic image: '*If he had shown me the X-ray and I could have been a person that wanted to know every little detail of it and it could have been five, ten minutes explaining. But he's got a pressure of a queue outside waiting to come in.*'

Variation and trends in responses

Many participants (12/25) provided mixed responses about wanting to view their images, they wanted and appreciated the opportunity to view some images but not others. However, six participants were unambivalently in favour of viewing their images, whilst five did not ever wish to see them. Two participants had never seen their own images said they would have liked to have had the opportunity. No particular pattern emerged regarding preference and age or sex, but we found a trend with respect to anatomy: patients were more eager to view pictures of the skeleton, whereas soft tissue, especially abdominal organs, elicited a higher level of squeamishness and a reduced desire to view the image. F11 expressed huge enthusiasm about viewing x-rays of her spine, but added, *"I'm not saying I'd want to look at my own tummy, you know, but to look at an X-ray is brilliant'*—X-ray clearly connoting 'bones' to her. On the other hand our pilot interviewee, who was not recruited from primary care commented that bony X-rays serve as a reminder of mortality, in contrast to, for instance, antenatal ultrasound, which this respondent characterized as being '*completely different*', and '*about life*'. The desire or lack of desire to see one's own image was also linked for some with the seriousness of the ailment, or the danger of planned procedure. One participant, F23, discussed her examination for two ailments, one respiratory and one spinal. She feared the effects of her spinal problem more than her respiratory complaint and thus felt a greater desire to view for herself the image of her spine: *'…I wasn't worried about wheezing with my chest, I mean I know it could be serious, but I didn't think it was serious, but I was very worried about my spine because I was worried I would be like it for the rest of my life…'*.

Those participants who did not want to see the image felt that shared viewing the image was a waste of time, their own and that of the clinician. F20, who had undergone a neck X-ray for persistent pain, probably arthritic, felt only added frustration at viewing the image in the company of the specialist nurse-practitioner: *' …no, I mean if you don't know what you're looking at then it's not really very helpful is it'*. She said that had it been an image of her child she would have certainly wanted to see the image. F2, aged 81, consulted her GP for a problem with her spine, and also discussed an experience getting an X-ray for a foot injury. She felt that it might be *'interesting'* to see the image, but went on to say

'Well really you rely on the doctor don't you to advise and you just go along with that, so you're hoping that you're getting the right medication…. I mean they've been through all their learning haven't they, and degrees and such like, and they know better than I do, hopefully'.

F3, who felt strongly that she better understood and dealt with her pain from a fractured thumb because she had viewed the X-ray herself, also commented on the importance of trusting the doctor, who told her he was *'happy with the positioning of the fracture'*. The positioning as viewed on the X-ray did not look right to F3, who said *'…We were slightly confused … but you're trusting that the doctor knows what he's talking about, so that was really it, that was basically what he said…'*.

Discussion

Statement of principal findings

While clinicians order diagnostic imaging with the aim of adding to their information about a patient's complaint, the images themselves, and their production, do more than convey clinical data. For our research participants, adults aged 40 and above living in the south of England who had recently undergone diagnostic imaging, the static medical image occupies multiple positions: it enhances the patient's understanding of his or her complaint; it has the potential for emotional impact (positive and negative), and it affects the nature of the doctor-patient encounter. The three themes identified in the data highlight the symbolic meanings attaching to *the act of viewing* the images alongside the doctor: 1) greater comprehension of the illness or injury; 2) the emotional effect linked to viewing one's 'invisible body'; and 3) the influence of shared viewing of the image on the social dynamic of the medical consultation.

Strengths and weaknesses in relation to other studies, discussing important differences in results

Unlike other studies this investigation included both men and women, and took a patient-centred perspective focusing on the *process* of sharing images in a clinical consultation, rather than taking a medicalised, illness-centric stance enquiring about a particular ailment or procedure. Previous research has focused on diagnostic sub-groups and specific technologies (e.g. older women and bone densitometry [12]; pregnancy and ultrasound [17], mammography [18] and hysteroscopy [19]). All of these studies focus on women, but Cohn [20] explores neurological or psychiatric patients their understanding of their brain scans. Radstake [6] conducted what she calls 'endography' (i.e. an inner-looking take on 'ethnography') of patients undergoing real-time imaging in a Dutch hospital. A recurrent theme in this stream of literature is a sense of patients' discomfort with the imaging and with technology more generally. Reventlow et al. [13-15] working with Danish women in their 60s, noted that the highly technological nature of the investigation created in these *asymptomatic* women a sense of weakness and vulnerability. Griffiths et al. [18] explored women's perspectives on breast screening and mammogram, again finding that the visualisation technology imposes on women a devaluation of their own breast and body

awareness, 'separating the at-risk breast from embodied experience'. Our work, however, suggests that for some patients, in some situations, viewing their own images generates an almost opposite reaction, one of enhanced empowerment and of reassurance.

Van Dijck writes that 'patients often blindly trust the panoptic nature of the mechanical-clinical eye' [21]. In this study, we find otherwise; patients are neither blindly trusting nor entirely certain of the role of the image in clinical care, but are, like their doctors, finding their way through the information available to the best possible solution for them. Merleau-Ponty [22, 23] argues that perception is an embodied experience; that viewing images, in the case of one's self, becomes incorporated into the individual's sense of himself or herself. Cohn [24] reports that patients who chose to view images from their brain scans regarded the image as validating the sensation, the experience of mental illness. Where other forms of communication like reports and numerical data seem inaccessible, and perhaps inapplicable, the picture itself embodies and thus represents in a simple and, according to Cohn, 'autonomous' manner the mental illness and consequent suffering of that particular patient. In the present study, we have explored the role of the image in dealing with physical illness and injury.

Meaning of the study: possible explanations and implications for clinicians and policy makers

Our own previous research suggests that physician opinion about sharing images with the patients varies, and that the reasons for the decision 'to share or not to share' range from the logistic to the philosophical. Mol [5] writes that x-rays are done 'one body at a time'; our aim in this project has been to understand the perspectives of people whose bodies, one at a time, were investigated. We have described both positive and negative attitudes of these respondents toward seeing images of the interior body. These affective responses around the viewing of images, however, are not uncomplicated or unmitigated; more cognitive considerations also come into play, including which part of the body has been imaged, the nature of the ailment, and indeed the nature of the patient. Thus we cannot reach simple conclusions or make recommendations as to whether and when sharing images with patients promote a good outcome

Limitations of our study

Weaknesses include the limited age range of our population; all the adults were 40 years or older, with an average age of 65 years. It would be interesting to find out what a younger generation of patients thinks about the experience of viewing their own medical images. The data were collected retrospectively and are thus reliant on participants' recall. The number and characteristics of patients who were eligible for inclusion in this study but declined to participate are not available to us; this was a condition of the research ethics committee approval. Finally, the study was based in the UK where the availability of medical images in the clinical setting may differ from other countries. In the UK there is ready access to medical images during consultations in secondary care health settings, but it is not normal practice for general practitioners, working in the community, to access their patient's images, even if theoretically possible [3, 25]. In primary care generally it is only the written report of the image that is available and accessed in the consultation, however one of our recruiting general practices was unusual in having well established, direct access to a community based imaging facility (digital X-ray, DXA, and MRI).

Unanswered questions and future research

The clinical encounter takes place, usually, in a dyadic form; in the present study, we queried only one half of the dyad with respect to the experience of viewing or not viewing a particular image. These physician's own point of view, his or her own reasons for deciding 'to share or not to share', remain opaque to us, reported if at all only by conjecture or hearsay on the part of our research participants. An investigation involving both halves of the pair would be a very useful addition to the project and build on the work we have already done with radiologists and GPs about sharing images with their patients [3].

Another, almost completely unexplored component of medical imaging is the role of the technician or technologist: the individual who makes the image. Some of our participants reported significant encounters with the technician, both in terms of the experience of producing the image, and in terms of learning something of the results. Current guidelines regarding patient-technician interactions allow for leeway depending on the seniority and position of the technician. Further exploration of the technician's role regarding patient viewing of images would be of interest.

In conclusion, for some patients the possibility of shared viewing of their of their own diagnostic images can be powerful and resonant experience in a variety of ways, including both better understanding of pain or other sensations associated with diagnosis, and building a stronger alliance between doctor and patient. The nature and form of our data collection precludes giving a prescribed course of action regarding the showing or not showing images to particular patients, but we can say that an open and frank discussion of the possibility of such sharing is recommended. Further, we hope our work stimulates discussion amongst clinicians who will be increasingly faced with the opportunity to share visual evidence of health and disease with their patients.

Details of contributors

Leslie Carlin (LC), Flis Henwood (FH) and Helen Smith (HS) developed the study idea and method. LC conducted the interviews. LC and HS read and coded the transcripts and interpreted the data. LC drafted the paper and HS and FH provided constructive feedback on all versions of the manuscript. Helen Smith is the guarantor of this paper.

Competing interest statement

All authors have completed the Unified Competing Interest form atwww.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

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There was no external funding for this project

Data sharing

No additional data available

Transparency declaration

Helen Smith (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained

Ethical approval

Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Reference number 09/H1102/105)

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Table 1: Characteristics of Interviewees (n=25)

Study ID (M=male; F=female)	Age at interview	Reason given by patient for imaging referral	Patient saw focal image	Has seen other medical images
F1	59	abdomen and chest x-rays (diverticulitis)	no	yes
F2	81	swollen knee x-ray	no	yes
F3	49	broken thumb x-ray	yes	yes
M4	83	swollen ankle x-ray	no	no
F5	44	head and neck MRI	yes	yes
F6	46	hip x-ray	yes	yes
M7	62	chest x-ray	no	yes
M8	76	hip x-ray	yes	yes
F9	49	chest x-ray (possible metastasis)	yes	yes
F10	72	chest/lung x-ray and CT fragility fracture leg, collarbone, x-ray and CT	yes	yes
F11	55	MRI	yes	yes
F12	71	spine; x-ray	no	yes
F13	41	back; x-ray and MRI	yes	yes
M14	49	chest x-ray	yes	yes
F15	74	back and torso x-ray	no	yes
M16	53	neck and shoulders; x-ray	no	yes
M17	83	spine; x-ray	yes	yes
M18	86	chest x-ray, MRI	no	yes
F19	65	mammogram	yes	yes
F20	48	neck x-ray	yes	yes
M21	74	hip x-ray	no	yes
F22	84	chest and foot x-ray	no	yes
F23	78	chest x-ray	yes	yes
M24	72	hip and spine x-ray and MRI	yes	yes
F25	75	arm x-ray	no	no

To see or not to see: a qualitative interview study of patients' views on their own diagnostic images

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Structured Abstract

Objectives - To ascertain what meaning individuals attach to perceiving images of their own interior body and how the images and their meanings affect the clinical consultation

Design - Face to face semi-structured interviews

Participants - 25 adult patients in southern England who within the preceding 12 months had been referred for diagnostic imaging

Setting - Community

Results - For patients, being shown their own X-rays, magnetic resonance images (MRIs) or computed tomography (CT) images creates a variety of effects: 1) a sense of better understanding of the diagnosis; 2) validation of their sensory and emotional response to the illness or injury; and 3) an alteration to the tenor and nature of the clinical encounter between patient and physician. In addition to meanings attached to these images, patients also impute meaning to the physician's decision *not* to share an image with them. The desire to see their image was greater in those patients with a skeletal injury; patients are less keen on viewing abdominal or other soft-tissue images.

Conclusions - Viewing images of one's interior, invisible body is powerful and resonant in a number of ways. The experience of not seeing, whether through the patient's or the physician's choice, is also fraught with meaning.

Article summary

Article focus

- There is a paucity of research involving diagnostic imaging in the context of clinical care rather than screening and preventative medicine. In addition, reports of men's perspective on viewing their own diagnostic images are mostly neglected. There has been no previous study exploring patients' reactions to seeing their own diagnostic images in consultation with their doctor.

Key messages

- The viewing their own static images create for patients a variety of effects: 1) a sense of better understanding of the diagnosis; 2) validation of their sensory and emotional response to the illness or injury; and 3) an alteration to the tenor and nature of the clinical encounter between patient and physician.
- In addition to meanings attached to these images, patients also impute meaning to the physician's decision *not* to share an image with them. The desire to see their image was greater in those patients with a skeletal injury; patients are less keen on viewing abdominal or other soft-tissue images.

Strengths and limitations

- Weaknesses include the limited age range of our population; all the adults were 40 years or older, with an average age of 65 years. It would be interesting to find out what a younger generation of patients thinks about the experience of viewing their own medical images.
- The data were collected retrospectively and are thus reliant on participants' recall. We queried only one half of the clinician-patient dyad with respect to the experience of viewing or not viewing a particular image. These physician's own point of view, his or her own reasons for deciding 'to share or not to share', remain opaque to us, reported if at all only by conjecture or hearsay on the part of our research participants.

Introduction

Medical imaging is used in health care for diagnosis, screening and for monitoring of both disease progression and treatment response. In England alone there were 38,805,537 imaging investigations conducted in the NHS during 2010/11 [1]. The armamentarium of imaging techniques has vastly expanded since Roentgen's discovery of X-rays in 1895, and the 'authority of the image' [2] ~~(page 20)~~ has also, correspondingly, increased. In the present paper we begin to explore the meanings imputed to 'still' images when they are shared, or not shared, with patients, and so focus on computed tomography (CT) and magnetic resonance imaging (MRI) along with X-rays.

Development of digital imaging technology enables wider dissemination of images within medicine, and has changed the way these pictures are accessed and used clinically [3]. The literature on the role of medical imaging techniques concentrates on practitioners and institutions, and largely lacks the patient's viewpoint. A ~~few exceptions are~~ notable ~~,~~ ~~including, the quite~~ exception~~al~~is the work by Blaxter, which explores her own experience as a patient looking for conflicting arguments about the ways in which medical technology, and in particular medical imaging, affect the management of illness and of doctor-patient relationships [4]. Blaxter describes how two opposing tropes have prevailed in describing the effects of medical technology on patients. In one the medical image might be seen as the oppressor of the patient, creating a situation in which 'technological representations hide the selves embedded in human bodies' ~~(page 763~~). In this view, patients are rendered passive in the face of a technology understood only by the experts; in their turn, medical

experts' attitudes toward the pre-eminence and efficacy of technology is reinforced by their patients' submissiveness to the authority of that technology.

An alternate perspective, ~~is~~ propounded by Mol [5] and others, ~~who~~ argue that rather than being alienated by high-tech medical procedures ~~,~~ patients, as well as practitioners, enlist their outputs both to manage their perceptions of themselves and their ailments, and to influence their treatment. Taking this vantage point, the body is not subdued by the image, nor is the patient rendered invisible by it, but rather the body is 'multiplied' to include 'the image as well as the reality' [4]~~(page 764). '[T]he recalcitrant public is an absent presence in many of the "problems with the public" in the public understanding of science.' Blaxter concludes that the alienation experienced by patients stems not from the technology or the images, but from the system in which both technology and the medical profession are bound: creating a case of problematic 'social adaptation' (page 775). Apart from Blaxter's contribution, however, exploration of patients and their static images, in which they remain still and 'actively learn to be bodies~~ Although other work exploring patients and their static images is largely absent ~~'~~ [6] ~~and where the image production occurs remotely, is largely absent.~~

~~In addition,~~ there has been an interesting thread in the medical anthropology and medical sociology literature exploring the role of women's experiences of particular screening and preventative medicine procedures: screening mammography ([7]), antenatal foetal ultrasound [8 - 11], and bone densitometry [12-15]. Unfortunately ~~T~~this research has not extended into ~~ere is however a paucity of research involving~~ ~~diagnostic imaging in~~ the context of general clinical care ~~rather than screening and preventative medicine~~and has

neglected ~~. In addition, reports of~~ the perspectives ~~men~~of men.~~'s perspective~~ ~~on viewing their own diagnostic images are mostly neglected.~~

In a previous project, we queried general practitioners (GPs) and consultant radiologists about the impact of sharing medical images with patients during consultations, and about the role of Picture Archiving and Communications (PACS) technology on the dissemination of diagnostic radiographic images beyond the hospital and into the arena of primary care [3]. In the current study, we shift the focus to the 'third leg' of the radiologist-clinician - patient tripod: the patient. Two central questions are addressed: i) what meanings do individuals attach to perceiving images of their own interior body? and ii) how do the images, and their meanings, affect the clinical consultation?

Methods

Participants and sampling

Twenty five patients from nine general practices in the south-east of England participated in this study (Table 1). A convenience sampling strategy was used, participants were recruited by eleven general practitioners who during the consultation enquired of the patients' willingness to participate in a semi-structured interview concerning their experiences of a recent referral from general practice for diagnostic imaging (X-ray, CT, or MRI). We focused on these modalities as they produce a static image that is viewed separately, as opposed to the dynamic procedure of ultrasonography (cf. Radstake [6]). The study inclusion criteria were: adult, fluent speaker of English, competent to consent, and had been referred to an outpatient imaging department within the past 12 months.

Interview procedure

Written consent was gained prior to beginning the interview, which was audio-recorded and professionally transcribed. All interviews were conducted by LC, an anthropologist by training. Topics included patients' experiences of undergoing an imaging procedure, their attitudes toward the viewing or not viewing the resulting images, and their beliefs and opinions concerning the place of such images in a clinical consultation. Descriptive (interview setting, participant behaviours) and reflective field notes were made during the interview process.

Analysis

Data were analysed following a qualitative descriptive method [16]. All transcripts were read and coded by two researchers (LC and HS), manually by both researchers, and using a computer-assisted qualitative data analysis program *(NVivo)* by one researcher (LC). Data were coded 'freehand' by creating as many new free nodes as seemed necessary, and then 'rolling up' nodes into hierarchies or trees. The freehand and the electronically-assisted coding produced very similar results.

Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Ref. no. 09/H1102/105).

Results

Twenty-five of 47 patients who expressed initial willingness to participate were interviewed; two potential participants changed their minds; the remainder were uncontactable, ineligible, or unavailable within the time frame of the project. Participants ranged from 41 to 86 years (mean age 65); nine (36%) were men. At the request of the ethics committee we did not count or collect information about the participants who declined the GPs invitation to participate. Most of the interviews were conducted in the participant's own home, but three individuals wished to be interviewed on university premises. Interviews ranged from 13 to 52 minutes, with a mean of 28 minutes.

While the patients were recruited on the basis of having undergone a recent diagnostic imaging procedure, sometimes other experiences of imaging also formed part of the discussion, for example earlier imaging experiences of themselves or others. Of the 25 participants, 14 (56%) reported having been shown the image that rendered them eligible for this study, and 23 (92%) spoke of how on some other occasion they had viewed images of themselves or of relatives (children, parents, spouses) (Table 1). In the results, to preserve anonymity, we use a convention of numbering participants, prefixed with 'M' to indicate a male and 'F' a female participant.

What the images mean to patients

Patients' opinions, wishes, and thoughts on images 'being shared with' varied, as did the meanings they took away from the experience—or the lack of the experience—of viewing their own interior. The themes that emerged from our coding formed three identifiable but interwoven strands, namely that being shown images 1) enhances understanding of the problem , 2) affects the emotional impact of diagnosis, and 3) changes the nature of the interaction with the physician during consultation.

Firstly, the patients who viewed their own images reported that doing so **enhanced their understanding** of their ailments. Seeing the image *informed*; it served as a visual aid in a basic pedagogical sense. In addition (one thread) the image also validated sensation—*'that's why it hurts like it does'* (participant F13). In either case, the result of seeing the image produced or enlarged knowledge *by* the patient *of* her own corpus, it linked body to mind;

several respondents commented that pain seemed easier to manage once they had seen its source 'for themselves'. F13 continues:

> *I think it was easy because then when he [physician] was talking about it and he could actually kind of point and see, so when someone is saying about the bottom disc missing from your spine you've got a vague idea of kind of where that is, but when you can actually look at it and he's pointing and showing you the different bits, and I think it actually helps you understand, it's not just some kind of airy fairy thing, it's actually there in front of you, and you can see it, and I think that's got to be a good thing.*

F3 concurred, saying *'…if I had any fractures in the future I would want to see the fracture because I think it helps you understand the pain, if that makes sense…He [the consultant] wasn't hugely informative but I think the x-ray picture said it all.'* In some cases, the expectation of knowledge emanating from the image was very high indeed, and possibly unrealistic in its reach: *'…If I was able to see the x-ray I might have been able to see something that, you know, where the pain is, and say to the doctor "Well that's where I'm getting this pain, that area there." And they might be able to either explode that image up and see if there is anything in that actual area'* (M16).

In a second theme, viewing the image had an ***emotional impact***, generally one of reassurance, and not necessarily reliant on greater comprehension of the medical facts of the case. For instance M8 described viewing an image of his lungs: *'I think this a modern sort of thing isn't it now? Where patients get to see x-rays. Good thing for settling you down and making you feel calmer I think, and being aware that there's nothing wrong. I mean most people haven't got any medical knowledge at all have they, to be quite honest. So they could have been sideways, upside down, I wouldn't have known the difference.'* participants often spoke of the importance of having trust or faith in the physician, whether GP or specialist, as being more important than seeing the image on which the doctor based his or her diagnosis or treatment recommendation: 'I've got faith in them, that their expertise is better than me looking at their pictures' (M8). Nonetheless, seeing the image for oneself

offered reassurance for *some* participants. F23, commenting on a recent spinal X-ray, remarked: *'I was relieved that I could see definitely having had it pointed out to me, what was wrong, and it wasn't anything that I could have avoided myself, that it was just the bones had come together, trapped the nerves, that was it, and I could see for myself what had happened.'* Other participants, however, felt added anxiety, as opposed to reassurance, about seeing an image that could convey bad news; for instance, a participant being investigated for possible lung cancer, F9, commented, *'I think it's a very grey area to want to see the X-ray if you don't know what you are looking for ….'.* M21 expressed a quite certain opposition to viewing his hip X-ray: *'…no, I don't think so, no, no, I don't want to look at it, I don't think so. I mean I don't want to see it to be honest… If it's bad I don't want to see it, you know, I can feel that it's not good, I know it's not good so I'll take that as evidence'*.

Finally, the third thematic strand in our analysis focuses on the impact of shared viewing of the medical image as ***changing the nature of the consultation with the physician***. Again, this theme comprises multiple threads. In one, we elucidate the manner in which the physical presence of the image serves as a focal point for both doctor and patient, changing the consultation dynamic. An example: F6, discussing her hip and lower spine X-ray, enthused, *'but to actually see it as a patient I think is invaluable really, I think it would be marvellous, and also in terms of mediating the relationship with your doctor because we're talking about a third thing, rather than it being… face to face…'*. This patient, an articulate woman familiar with medical argot and medical practitioners, finds comfort in having the image serve as a point of common interest, rather than she, as the patient, being the sole focus of the medical gaze. For other participants, the image almost becomes a third 'actor', more than a 'thing', within the room, exemplified by several quotes beginning *'The x-ray says*'; for instance, *'[T]he X-ray says arthritis'* (M24). The image, however, may attract the attention of the physician at the expense of the attention paid to the actual patient in the room, or, as in the case of participant M24, give the impression that the physician's opinion is at odds with the diagnosis 'made' by the image: *'I could tell he didn't quite agree with this X-ray. But he didn't say that. They don't say, "I don't agree with it."'*

The very decision made by the physician as to *whether* to show the image to the patient affects the way the patient understands the relationship between themselves and the doctor. Respondents with whom the doctor had deliberately shared an image felt more part

of the consultation, and sometimes of the treatment decisions. They also felt more respected and valued by their doctor, both because to share the image took more time than not to, and because the expectation of interest, even without comprehension, in the anatomical facts suggested that the doctor had a high opinion of the patient as a person. The act or fact of sharing implied respect and concern *'…because you feel they've taken the time to show you. You feel they care a lot'* (M24). F1, suffering from an abdominal complaint, commented:

> *I suppose it would be- yes, very sort of empowering in a kind of way if somebody had time to say "This is the X-ray, this is the thing we found, this is where the disintegration is but this bit's all right." I think yes it would be good, but I think it would so far exceed my expectations because of the lack of time that people have that it wouldn't even come into my head to think that it might be possible.*

M16 talks about his experience of seeing X-rays of his hip and shoulder, saying *'I think it brings you a little bit closer to the doctor and a bit more rapport with them. That's what I just feel.'* However, the effect of the clinician's decision about shared viewing of an image is perhaps conveyed most clearly by the comments of participants whose doctors chose *not* to share with them an image which the doctor was currently scrutinising. M24, speaking of his hip and spine X-ray, said *'[In]… fact I didn't ask because I don't think I'd know anything about it anyway. I wouldn't know anything on the X-ray. He could tell me, but I just felt – I didn't ask, so he wasn't going to show it'*. This respondent had caught a brief glimpse of the image on the doctor's monitor, which the doctor gazed at during the consultation, *'It's white, it's a light, it attracts your eye'*. This respondent disparaged his own intelligence when trying to explain why his doctor denied him a look at the image himself: *'I guess he has pressure, his other patients. And, but yes, he's very good. He would answer any questions I asked him. It's only our ignorance that we don't know what to ask…'*. From our interview, it is clear that this man had wit enough to ask thoughtful questions about his spinal disc problem and in response to a question about why he wanted to view the image, he replied, *'I suppose it makes you feel a little bit more involved, a bit more interested, or a bit more involved in what's going on inside you, because it is your body. They would be sort of, kind of added extras. I could have come out and said, "Do you know what, they've showed me my back."'* Another respondent, F9, reported noticing a CT image of her kidneys on the monitor on her

doctor's desk. *'And I was sort of looking at it, and he went "Oh, that's not for you to see" and turned the screen, the computer screen [away]*'. Other respondents expressed concern about the added time it would take a doctor to show and explain the image. F22 felt that she would like to view images of her foot X-ray, but commented: *'It would be interesting yes, but I would think it's a time factor with lots of doctors having to stop and show people and explain everything.'* M24 concurred with respect to his lower back and pelvic image: '*If he had shown me the X-ray and I could have been a person that wanted to know every little detail of it and it could have been five, ten minutes explaining. But he's got a pressure of a queue outside waiting to come in.*'

Variation and trends in responses

Many participants (12/25) provided mixed responses about wanting to view their images, they wanted and appreciated the opportunity to view some images but not others. However, six participants were unambivalently in favour of viewing their images, whilst five did not ever wish to see them. Two participants had never seen their own images said they would have liked to have had the opportunity. No particular pattern emerged regarding preference and age or sex, but we found a trend with respect to anatomy: patients were more eager to view pictures of the skeleton, whereas soft tissue, especially abdominal organs, elicited a higher level of squeamishness and a reduced desire to view the image. F11 expressed huge enthusiasm about viewing x-rays of her spine, but added, *"I'm not saying I'd want to look at my own tummy, you know, but to look at an X-ray is brilliant'*—X-ray clearly connoting 'bones' to her. On the other hand our pilot interviewee, who was not recruited from primary care commented that bony X-rays serve as a reminder of mortality, in contrast to, for instance, antenatal ultrasound, which this respondent characterized as being '*completely different*', and '*about life*'. The desire or lack of desire to see one's own image was also linked for some with the seriousness of the ailment, or the danger of planned procedure. One participant, F23, discussed her examination for two ailments, one respiratory and one spinal. She feared the effects of her spinal problem more than her respiratory complaint and thus felt a greater desire to view for herself the image of her spine: *'…I wasn't worried about wheezing with my chest, I mean I know it could be serious, but I didn't think it was serious, but I was very worried about my spine because I was worried I would be like it for the rest of my life…'*.

Those participants who did not want to see the image felt that shared viewing the image was a waste of time, their own and that of the clinician. F20, who had undergone a neck X-ray for persistent pain, probably arthritic, felt only added frustration at viewing the image in the company of the specialist nurse-practitioner: *' …no, I mean if you don't know what you're looking at then it's not really very helpful is it'*. She said that had it been an image of her child she would have certainly wanted to see the image. F2, aged 81, consulted her GP for a problem with her spine, and also discussed an experience getting an X-ray for a foot injury. She felt that it might be *'interesting'* to see the image, but went on to say

'Well really you rely on the doctor don't you to advise and you just go along with that, so you're hoping that you're getting the right medication…. I mean they've been through all their learning haven't they, and degrees and such like, and they know better than I do, hopefully'.

F3, who felt strongly that she better understood and dealt with her pain from a fractured thumb because she had viewed the X-ray herself, also commented on the importance of trusting the doctor, who told her he was *'happy with the positioning of the fracture'*. The positioning as viewed on the X-ray did not look right to F3, who said *'…We were slightly confused … but you're trusting that the doctor knows what he's talking about, so that was really it, that was basically what he said…'*.

Discussion

Statement of principal findings

While clinicians order diagnostic imaging with the aim of adding to their information about a patient's complaint, the images themselves, and their production, do more than convey clinical data. For our research participants, adults aged 40 and above living in the south of England who had recently undergone diagnostic imaging, the static medical image occupies multiple positions: it enhances the patient's understanding of his or her complaint; it has the potential for emotional impact (positive and negative), and it affects the nature of the doctor-patient encounter. The three themes identified in the data highlight the symbolic meanings attaching to *the act of viewing* the images alongside the doctor: 1) greater comprehension of the illness or injury; 2) the emotional effect linked to viewing one's 'invisible body'; and 3) the influence of shared viewing of the image on the social dynamic of the medical consultation.

Strengths and weaknesses in relation to other studies, discussing important differences in results

Unlike other studies this investigation included both men and women, and took a patient-centred perspective focusing on the *process* of sharing images in a clinical consultation, rather than taking a medicalised, illness-centric stance enquiring about a particular ailment or procedure. Previous research has focused on diagnostic sub-groups and specific technologies (e.g. older women and bone densitometry [12]; pregnancy and ultrasound [~~16~~17], mammography [18~~17~~] and hysteroscopy [19~~18~~]). All of these studies focus on women, but Cohn [20~~19~~] explores neurological or psychiatric patients their understanding of their brain scans. Radstake [6] conducted what she calls 'endography' (i.e. an inner-looking take on 'ethnography') of patients undergoing real-time imaging in a Dutch hospital. A recurrent theme in this stream of literature is a sense of patients' discomfort with the imaging and with technology more generally. Reventlow et al. [13-15] working with Danish women in their 60s, noted that the highly technological nature of the investigation created in these *asymptomatic* women a sense of weakness and vulnerability. Griffiths et al. [18~~17~~] explored women's perspectives on breast screening and mammogram, again finding that the visualisation technology imposes on women a devaluation of their own breast and body

awareness, 'separating the at-risk breast from embodied experience'. Our work, however, suggests that for some patients, in some situations, viewing their own images generates an almost opposite reaction, one of enhanced empowerment and of reassurance.

Van Dijck writes that 'patients often blindly trust the panoptic nature of the mechanical-clinical eye' ~~(~~[21~~20]: 8)~~. In this study, we find otherwise; patients are neither blindly trusting nor entirely certain of the role of the image in clinical care, but are, like their doctors, finding their way through the information available to the best possible solution for them. Merleau-Ponty [~~21,~~ 22,23] argues that perception is an embodied experience; that viewing images, in the case of one's self, becomes incorporated into the individual's sense of himself or herself. Cohn [24~~3~~] reports that patients who chose to view images from their brain scans regarded the image as validating the sensation, the experience of mental illness. Where other forms of communication like reports and numerical data seem inaccessible, and perhaps inapplicable, the picture itself embodies and thus represents in a simple and, according to Cohn, 'autonomous' manner the mental illness and consequent suffering of that particular patient. In the present study, we have explored the role of the image in dealing with physical illness and injury.

Meaning of the study: possible explanations and implications for clinicians and policy makers

Our own previous research suggests that physician opinion about sharing images with the patients varies, and that the reasons for the decision 'to share or not to share' range from the logistic to the philosophical. Mol ~~(2002)~~ [5] writes that x-rays are done 'one body at a time'; our aim in this project has been to understand the perspectives of people whose bodies, one at a time, were investigated. We have described both positive and negative attitudes of these respondents toward seeing images of the interior body. These affective responses around the viewing of images, however, are not uncomplicated or unmitigated; more cognitive considerations also come into play, including which part of the body has been imaged, the nature of the ailment, and indeed the nature of the patient. Thus we cannot reach simple conclusions or make recommendations as to whether and when sharing images with patients promote a good outcome~~. For some patients the possibility of shared viewing of their of their own diagnostic images can be powerful and resonant experience in a variety of ways, including both better understanding of pain or other~~

~~sensations associated with diagnosis, and building a stronger alliance between doctor and patient. The nature and form of our data collection precludes giving a prescribed course of action regarding the showing or not showing images to particular patients, but we can say that an open and frank discussion of the possibility of such sharing is recommended. Further, we hope our work stimulates discussion amongst clinicians who will be increasingly faced with the opportunity to share visual evidence of health and disease with their patients.~~

Limitations of our study

Weaknesses include the limited age range of our population; all the adults were 40 years or older, with an average age of 65 years. It would be interesting to find out what a younger generation of patients thinks about the experience of viewing their own medical images. The data were collected retrospectively and are thus reliant on participants' recall. The number and characteristics of patients who were eligible for inclusion in this study but declined to participate are not available to us; this was a condition of the research ethics committee approval. Finally, the study was based in the UK where the availability of medical images in the clinical setting may differ from other countries. In the UK there is ready access to medical images during consultations in secondary care health settings, but it is not normal practice for general practitioners, working in the community, to access their patient's images, even if theoretically possible [3, 25]. In primary care generally it is only the written report of the image that is available and accessed in the consultation, however one of our recruiting general practices was unusual in having well established, direct access to a community based imaging facility (digital X-ray, DXA, and MRI).

Unanswered questions and future research

The clinical encounter takes place, usually, in a dyadic form; in the present study, we queried only one half of the dyad with respect to the experience of viewing or not viewing a particular image. These physician's own point of view, his or her own reasons for deciding 'to share or not to share', remain opaque to us, reported if at all only by conjecture or hearsay on the part of our research participants. An investigation involving both halves of the pair would be a very useful addition to the project and build on the work we have already done with radiologists and GPs about sharing images with their patients [3].

Another, almost completely unexplored component of medical imaging is the role of the technician or technologist: the individual who makes the image. Some of our participants reported significant encounters with the technician, both in terms of the experience of producing the image, and in terms of learning something of the results. Current guidelines regarding patient-technician interactions allow for leeway depending on the seniority and position of the technician. Further exploration of the technician's role regarding patient viewing of images would be of interest.

In conclusion, ~~. F~~for some patients the possibility of shared viewing of their of their own diagnostic images can be powerful and resonant experience in a variety of ways, including both better understanding of pain or other sensations associated with diagnosis, and building a stronger alliance between doctor and patient. The nature and form of our data collection precludes giving a prescribed course of action regarding the showing or not showing images to particular patients, but we can say that an open and frank discussion of the possibility ~~of such~~of such sharing is recommended. Further, we hope our work stimulates discussion amongst clinicians who will be increasingly faced with the opportunity to share visual evidence of health and disease with their patients.

Details of contributors

Leslie Carlin (LC), Flis Henwood (FH) and Helen Smith (HS) developed the study idea and method. LC conducted the interviews. LC and HS read and coded the transcripts and interpreted the data. LC drafted the paper and HS and FH provided constructive feedback on all versions of the manuscript. Helen Smith is the guarantor of this paper.

Competing interest statement

All authors have completed the Unified Competing Interest form atwww.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Details of funding

There was no external funding for this project

Data sharing

No additional data available

Transparency declaration

Helen Smith (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained

Ethical approval

Ethical approval for the study was granted by the South East Coast Research Ethics Committee (Reference number 09/H1102/105)

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Table 1: Characteristics of Interviewees (n=25)

Study ID (M=male; F=female)	Age at interview	Reason given by patient for imaging referral	Patient saw focal image	Has seen other medical images
F1	59	abdomen and chest x-rays (diverticulitis)	no	yes
F2	81	swollen knee x-ray	no	yes
F3	49	broken thumb x-ray	yes	yes
M4	83	swollen ankle x-ray	no	no
F5	44	head and neck MRI	yes	yes
F6	46	hip x-ray	yes	yes
M7	62	chest x-ray	no	yes
M8	76	hip x-ray	yes	yes
F9	49	chest x-ray (possible metastasis)	yes	yes
F10	72	chest/lung x-ray and CT fragility fracture leg, collarbone, x-ray and CT	yes	yes
F11	55	MRI	yes	yes
F12	71	spine; x-ray	no	yes
F13	41	back; x-ray and MRI	yes	yes
M14	49	chest x-ray	yes	yes
F15	74	back and torso x-ray	no	yes
M16	53	neck and shoulders; x-ray	no	yes
M17	83	spine; x-ray	yes	yes
M18	86	chest x-ray, MRI	no	yes
F19	65	mammogram	yes	yes
F20	48	neck x-ray	yes	yes
M21	74	hip x-xray	no	yes
F22	84	chest and foot x-ray	no	yes
F23	78	chest x-ray	yes	yes
M24	72	hip and spine x-ray and MRI	yes	yes
F25	75	arm x-ray	no	no

Research Checklist

This checklist includes the original protocol and a COREC check list

Provisional research plan: patient perspective of viewing images (PACS and patients = PaP)

Principal and secondary research questions:

1. 'How does viewing their own radiograph or other scan as part of a clinical consultation affect patients?'

2. Secondary objectives include 1) exploration of the valence of any effect (positive or negative) of having viewed the image during a consultation; 2) investigation of constructive 'after effects' of viewing such an image, e.g. around comprehension of a diagnosis or compliance with treatment.

Summary of study:

This research project is designed to explore the impact on patients of viewing their own radiologic images: mainly x-rays, but also MRIs and CT scans. There is a dearth of information available about how sharing x-ray and other radiologic images with patients affects the clinical consultation. Currently in the UK, a GP may refer a patient to radiology services for investigation of a problem; a radiologist then views the image and sends a report back to the referring physician for discussion of diagnosis and any treatment. Increasingly with the advent of Picture Archiving and Communications Systems (PACS) within the NHS, it is feasible that the image will accompany the report, and the GP will be able to share both information and image with his or her patients. We wish to investigate the impact of 'sharing images with patients' (SIP) on the patient and more generally on the patient journey. There is a large literature concerning the use of digital radiologic images for diagnosis and teaching within medicine, and for remote medical care, but relatively little on the impact of sharing such images with patients themselves. What research exists, has been conducted with regard to specific health issues in women at particular life stages, e.g. bone densitometry scans, mammography, or fetal ultrasonography. Research on health literacy has reviewed the use of pictorial modes of communication and found them to be of great use in some circumstances, so it is reasonable to think that images of their own bodies will be effective in communicating with patients. Our previous research investigated consultant radiologists' and GPs' views on PACS in a previous study; our current aim is thus to explore the third 'leg' of the 'tripod': patients' perspectives on a) viewing their x-rays, b) the role of x-rays in the 'patient journey', and c) experience of x-ray services.

Summary of main issues:

The main ethical issues revolve around a) being sensitive to participants' own concerns that are distinct from our research interests and b) maintaining privacy and confidentiality. Point

Research Checklist

(a) will be addressed by targeting patients who are unlikely to be in situations that arouse particular alarm (i.e. in non-acute and non-life-threatening condition). To maintain privacy and confidentiality (point b), utmost care will be taken to conduct interviews in private, to use coding to protect identities, and to destroy and discard any personal or identifying information pertaining to individuals who may be contacted but decline to participate.

Scientific justification:

With film x-rays, the typical route for a patient referred from primary care involved a picture being viewed by a radiologist or other specialist, followed by a report transmitted to the GP, who fed back to the patient based on a written report. With the advent of PACS and filmless technology, the roll-out of PACS to primary care settings is in process. Once this is in place, it is envisioned that both report and image will be transmitted to the primary care physician. How will this affect the consultation? In what situations is the visual imagery useful, or perhaps detrimental? In our previous research, we explored the attitudes and beliefs of GPs and of consultant radiologists toward this 'sharing of images with patients' (SIP); our analysis suggests that both benefits and drawbacks accrue to the general practitioner from such a system. To our knowledge, no exploration has as yet been conducted about the impact of viewing their own radiographic image on patients within a consultation; the current project is designed to remedy that omission.

The proposed project is an outgrowth of previous research which was approved and funded by the Brighton and Sussex Medical School [details], results of which have been presented at professional conferences and are currently under review for a scientific journal. The research questions to be addressed here are of a developmental nature and are intended to lead to an application for a grant in the near future.

Design and methods:

We intend to recruit patients referred to the imaging service from primary care at the outpatient clinic, either polyclinic or hospital outpatient facility. Patients will be asked either while waiting for their appointment, or just afterward, whether they would consider talking with a researcher after receiving their results, about their experience of undergoing an x-ray [or other procedure] and about the subsequent consultation. An information leaflet with contact details will be provided, and it will be made clear that opting out at any time is possible.

Participants in the study will be recruited from those patients referred by GPs for outpatient x-ray or scan procedures. A small number (yet to be determined) of GP surgeries will be invited to cooperate in this developmental phase, and cooperating GPs will ask patients who meet the inclusion criteria whether a researcher may contact them by phone, post, or email after their imaging procedure. If the patient agrees, a researcher (LC) will contact them by the agreed method some time after their procedure to arrange an interview. A consent form will be sent to them prior to the arranged meeting, and the interview will proceed only after the consent form is signed. Thus consent will be obtained in a two-stage process: first, consent for the researcher to contact the participant at an appropriate date, and second, consent to being interviewed.

Research Checklist

We will request contact details for those who agree to participate, and will contact them by their preferred route (phone, post, or email) about a week after the procedure, to catch them as soon after any follow-up consultation as possible.

We anticipate a developmental phase to the study in which semi-structured interviews with the first 3 or 4 patients will frame a series of questions to be consistently included in interviews with the formal sample of approximately 25 patients.

In our previous project, we found that interviews with just over 30 individuals in two professional groups (GPs and radiologists) gave us data saturation; further data collection was unlikely to provide new information. Since the aim of this research is to develop a broad outline of the experience of viewing medical images, we feel that a similar point of data saturation will be reached with 25-30 participants. Reventlow et al. (2006) describe a study of women learning their results of a bone density scan by viewing charts and images; in that project, 16 respondents were included. Because we anticipate interviewing patients some of whom have and some who have not viewed their own radiologic images, we are aiming for a higher total number.

Interviews are anticipated to last approximately 30 minutes; they will be conducted by Dr. Leslie Carlin; location will be flexible for convenience of participants (most likely to be face-to-face in a GP surgery if room available, alternatively, at the university, or in patient's home, or by telephone.

Initial questions we wish to include:

* Introduce our research as being about the use of x-rays or scans in consultations
* Name, age, gender, birthplace [if non-local, how long living in Sussex- see below]
* For what complaint were you referred to the hospital/clinic for an x-ray/scan?
* What sort of information were you given by the technician who took the x-ray/scan?
* How long was the wait if any between referral, procedure, and learning results?
* If you met with someone to discuss your results, who did you meet, and where?
* How was that information presented [probe for clarity, sympathy, patience]?
* Did [whoever] show you the x-ray/scan during your consultation? if yes:
  * Did you think it was a good thing to be able to see the picture of your [blank]? If yes, why? If no, why not?
  * Did [whoever] use the picture in his/her explanation to you about your results? If yes, in what way was the picture useful?
* [if relevant, may follow up with questions about similar procedure in place of origin]

The data will be transcribed and all transcripts read by one researcher (LC). The transcripts will be entered into NVivo, a computer-assisted qualitative data analysis program, which facilitates creative consideration and evaluation of verbal data in a variety of ways, and also serves as a tool for developing draft reports. The theoretical perspective will make sensible use of a grounded theory approach (taking the data as they come, without preconceptions) but will also take on board Merleau-Ponty's (1962) argument that perception is an embodied experience, i.e. that viewing images, in this case of one's self, becomes incorporated into the individual's sense of himself or herself.

Involvement of patients and service users:

Research Checklist

The set of interview questions will be trialled on the first few respondents and the interview schedule reviewed modified if necessary. All participants (who are both patients and service users) will be essential in managing and undertaking the research, as only their cooperation will drive it forward. As this is a qualitative study, analysis relies on the patients responding in a thoughtful and analytic manner to our proposed questions. Finally, all participants will be offered the opportunity to receive their own lay account of findings in writing, or to meet with the researchers in person.

Inclusion/exclusion criteria:

Inclusion: adult patients referred by their GP for outpatient X-ray. Exclusion: patients who cannot give own consent (some learning disabled or psychiatric patients); patients deemed by the referring GP as vulnerable; patients whose referral is deemed by the referring GP to be for reasons that are likely to be traumatic.

Risks and risk management:

Potential risks and burdens to respondents include the intrusion of contact with a researcher, and possible distress at re-living an uncomfortable experience. We will not encourage people to participate in the project unless they are freely willing, and will clarify that they may withdraw at any point, even mid-interview. The interviewer is an anthropologist experienced at conducting face-to-face research who will use her own judgement to as well to ascertain that participants are comfortable being part of the project.

Interviews will be conducted in a location agreed by both participant and researcher, designed to be comfortable for the participant. Attention to privacy will be foremost although we remain sensitive to the fact that for some respondents, company might be desirable. The interviewer (Dr. Leslie Carlin) is an anthropologist and is experienced at discussing unusual topics with people. The interview is semi-structured, so that respondents will be able to guide the discussion in a direction that is comfortable to them- there are no questions that they have to answer. Privacy and confidentiality will be maintained throughout data collection, analysis, and reporting.

Risks to researchers are minuscule, and are limited to personal security in certain interviewing situations. The risk can be minimised by utilising an automated security reporting system (CRYSIS). Common sense will prevail, and if the interviewer feels threatened or even uncertain, she will abort the meeting.

Confidentiality and data protection:

Participants will be pseudonymised and a coded key kept electronically in a password-protected location. Any paper notes that include personal data will be stored in a locked filing cabinet in a locked office in a secure building on the university campus.

Information will be stored on password-protected computer accounts held and secured by the University of Brighton. Any work on this information done from the researcher's home can also be done via a secure network directly to the the university system, so that no personal data relating to participants need be stored on home computer or laptop. Paper-based information will be stored in a locked filing cabinet in a locked (when unoccupied) office, in a secure building on the university campus.

Research Checklist

It is likely that personal and potentially identifying information will be stored on and transferred between work (university) and home computers, via email or other network. Direct quotations may be used in reports and publications. Address or phone numbers will most likely be used for contacting participants and for making arrangements to meet. The interviews will be audio-taped for later transcription.

Paper data will be stored in locked filing cabinets; electronic files in a password-protected account belonging to Prof. Helen Smith, on the university's mainframe computer. Data will be stored for up to 10 years, as it is hoped that this project will generate a further program of work.

Research Checklist

Transparency declaration Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

Table 1
Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		

Table 1

Research Checklist

No	Item	Guide questions/description
		interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned No	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking No	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

Research Checklist

No	Item	Guide questions/description
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? *e.g. face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? *e.g. home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the