

REVIEW

Medical photography: ethics, consent and the intersex patient

S. CREIGHTON, J. ALDERSON*, S. BROWN and C.L. MINTO

Department of Obstetrics & Gynaecology, University College London Hospitals, University College, London, and

**Leeds Teaching Hospitals, Leeds, Yorkshire*

Introduction

Clinical photographs in journals and textbooks catch the eye and draw the attention. Authors are encouraged to submit illustrations to enliven otherwise dry pages of text. It is also assumed that clinical photographs are important in medical education. However, to date, clinical photography has been entirely a 'one-way' process. The clinicians reap any benefits and little attention is paid to the person within the photograph.

The patient in a medical photograph is often seen as an interesting case or unusual finding rather than a living, feeling person. Many doctors may not even be aware that consent should be obtained for a photograph, just as it is for any other procedure. To submit to medical photography may be considered a medical intervention and yet, to our knowledge, there are no data on the impact that being photographed may have on the patient and their family. This is particularly true for patients with intersex conditions, who are classically photographed naked.

The General Medical Council (GMC) clearly states [1] that 'Patients must be able to trust doctors with their lives and well-being. As a doctor you must; make the care of your patient your first concern, respect patients dignity and privacy, respect and protect confidential information, avoid abusing your position as a doctor and listen to patients and respect their views'. Feedback from patients at two UK adult intersex clinics has highlighted major concerns over possible long-term psychological damage attributable to clinical photography. Does subjecting an intersex patient to photography compromise these duties of care? It is time to critically evaluate the role of medical photography and review the principles of good practice for obtaining and storing images. Guidelines for consent and data protection issues must be widely available and used. It is also becoming clearer that medical photography is not a 'neutral act' and may

have detrimental effects on the patients that doctors are helping.

In this review we discuss the effects that photography may have on the patient and present information obtained from our intersex services and research. After much debate, we decided to publish two intersex women's clinical photographs, with their quotes, so that everyone can evaluate the ethical issues involved. We fully expect to be accused of perpetuating the practices that this paper is highlighting. However, both the individuals concerned have given full consent to their photographs being published for this purpose, as they both feel so strongly about the detrimental effects of clinical photography in intersex people. Whilst both of these photographs were taken in the late 1960s, this remains standard medical practice today, with most textbooks and even the most prestigious journals publishing pictures of identifiable naked adults [2] and children [3].

The use of clinical photography

The use of clinical images falls into three separate areas: for education, for publication and those necessary as part of the patient's hospital records. Clinical indications for photographs are common in certain specialities, e.g. dermatology, orthopaedics, oncology and plastic surgery, and can be an important part of medical care. For example, in dermatology photography is an objective way of comparing the progression of skin disease. As such these photographs are an integral part of the patient's medical notes and should be available to the clinician at each attendance. In intersex patients it can be helpful to have a record of ambiguous genitalia before surgery, as descriptive clinical terms and measurements can vary in interpretation and meaning between individual clinicians, and different specialities. There are also times when photography is necessary for forensic reasons, as in suspected intentional injury. However, a large proportion of medical photography is obtained

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for publication in journals or textbooks and for teaching and conference presentations. It is essential that this is recognized and that it is clear to patients what the purpose of the photograph is when obtaining consent for the photograph.

Types of clinical photography

Clinical photographs can be of a small area or a larger region of the body; occasionally an image of the whole patient naked is considered necessary. The photograph may show clinical features or illustrate surgical techniques. Photographs may be taken while the patient is under anaesthetic in theatre, or while awake in either a hospital ward or clinic, or the hospital's photography department. The images may be taken by a medical photographer or by an interested clinician with their own camera. The advent of digital cameras has made the latter situation more tempting.

Individuals may differ in their response to being photographed and to the subsequent use of the image. It is likely that the psychological response to both of these aspects of clinical photography would vary with the type of condition the patient has, their age, the photographic environment, the area of the body being photographed, and the empathy and sensitivity of the photographer. It is reasonable to assume that taking pictures of intimate areas such as breasts and genitals, or a naked full body, would be more likely to cause psychological distress. Even with the most thoughtful and sensitive photographer, it has been recognized that undergoing clinical photography 'can be an uncomfortable, undignified and degrading experience from (the) patient's point of view' [4]. Relevant to intersex patients is the additional intense stigma and embarrassment often felt in having this condition, from both societal and the patient's attitudes.

Current practice and standards for good practice in medical photography

Guidance as to what constitutes good practice in obtaining and storing clinical images can be obtained from several sources, including the GMC, the Institute of Medical Illustrators (IMI) [5] and the International Committee of Medical Journal Editors [6]. Individual hospital trusts should develop protocols and clear consent forms for clinical photography, with a signature required to consent for every possible use of the image [7].

Suggested standards for good practice in obtaining medical images are:

- Informed consent for **each** use of the image must always be obtained from the patient or guardian.
- Specific and fully informed consent to photography should always have been sought and granted before any photography takes place.
- This consent may be withdrawn at any time.
- The photograph should ideally be taken by a trained medical photographer in a suitable environment.
- The photographer must at all times respect the rights and dignity of the patient.
- All images must be stored in a safe and regulated environment, with controlled access.
- Complete anonymity is impossible and the minimum area of the body possible should be photographed.
- Boxes or shading over the eyes do not protect anonymity [7] and should not be used. Only in those cases where the face is essential to the image should this area be photographed.

The IMI has a Code of Responsible Practice which gives guidelines to its qualified Members on the full informed consent procedure required before clinical photography should take place and the conduct required of a medical photographer [5]. These are only guidelines or recommendations; medical photographers are not (yet) a registered body of practitioners. Senior medical photographic staff who are involved in managing departments and in training junior staff should ensure that adequate consent procedures are in place, that these procedures are followed carefully by their photographic staff, and that at all times attention is paid to maintaining the dignity of the patient during the procedure.

Medical images are now covered by the Data Protection Act and therefore have to be held securely, must be identifiable and traceable to an individual patient, and available for that patient to see if they follow the correct and published procedure for access to their clinical records. The implications of this are severe, especially considering the increasing use of digital cameras. While there is still nothing to stop any member of staff in a healthcare institution taking medical photographs, the responsibility for the after-care, storage, retrieval, duplication and use of these images is better handled by a central unit, normally the medical photography or illustration department. There are also increased responsibilities on the clinical users of such images, as it is now very easy to duplicate and disseminate images electronically, thereby contravening the terms of the Act.

Dilemmas in obtaining, storing and using clinical images

Unfortunately, informed and specific consent for clinical photography is not always obtained and it is in these instances, and those where additional, subsequent use is

made of the photographs, that problems and ethical dilemmas may occur. Medical photographers and illustrators (the two terms are often synonymous) also face dilemmas in permitting and controlling the use of the photographs they produce, especially where medical staff in their establishment move on or change for a variety of reasons over a long period.

Most illustration departments produce a set of images of a patient for the hospital notes that may be in either print or transparency form. Most will also keep a 'master' set of those images in the department, filed under a unique identifier to that patient and photographic session. Many will also provide either the master set or even a third set in an image library, to which bona fide medical and teaching staff have access and who may request duplicate sets for professional or even unspecified use. Still more sets may have been requested at the time of the original photography request for the image collections of other consultants or senior staff. Medical illustration staff have few powers or rights in policing who has the authority to order and use these images; they are often regarded merely as 'image technicians', there to produce the required images to order, and can be seen as obstructive if they question the use to which these images may be put.

It is obvious, from the permutations described above, that there may be many copies of a patient's images (some in film format, some electronic) in circulation and in use by different medical and healthcare personnel, and this can lead to situations which can be morally and ethically challenging.

Clinical perspectives

There is a wide range of intersex conditions; some such patients will have genitalia that are considered ambiguous, i.e. neither clearly male nor clearly female. Other intersex patients will have unambiguous genitalia but a karyotype will show that they have an unexpected sex chromosome pattern for their phenotype, e.g. a 46XY female or 46XX male. The incidence of intersex conditions is unknown, but estimates suggest that 0.1–2% of people may have an intersex condition [8].

Intersex conditions are rarely discussed in the general population and the individuals concerned often experience significant psychological distress, facing great stigma and isolation. Within our intersex services and from feedback via the Androgen Insensitivity Support Group [9], we have learnt that many adult intersexuals report sometimes feeling 'like a freak' and having low self-esteem. Intersex adults see many factors as vital in reinforcing these negative feelings. These include genital surgery with repeated vaginal examinations throughout childhood and adolescence, clinical photography, being

exhibited to many trainee doctors and medical students, and confusion caused by limited or inconsistent information about their actual diagnosis.

In women with unambiguous genitalia and a 46XY karyotype, e.g. complete androgen insensitivity (CAIS), previously called testicular feminization, there are usually no clinical signs in childhood. These patients have normal female external genitalia, with a shortened vagina, internal testes and no uterus. As these girls pass through puberty they develop normal secondary sexual characteristics, except for a reduced amount of pubic and axillary hair and primary amenorrhoea. Childhood clinical photography in these patients will show a normal healthy girl. The ethics of clinical photography in these cases are debatable and the process of having the photograph taken, along with its subsequent use, may be extremely traumatic and restrict adjustment to their condition. That they have what is considered a 'rare and intriguing' medical condition is no justification to photograph the patient.

"I have always been shocked at there being such a photo in my records and can see no reason for this photo, other than as some kind of "freak show" for other medical professionals. I have always thought the photo should have carried the caption of what the doctors were obviously thinking when they took it, i.e. 'Have you ever seen a genetic male looking so female?' I think the particular expression on my face speaks volumes and I was obviously traumatized by it" (Fig. 1).

Unlike CAIS, other intersex conditions may cause the birth of children with ambiguity of the genitals or developing ambiguous genitals in puberty. In these cases there are valid clinical signs, and clinical photography may have an important role both in recording information for the patient's medical records and for educational purposes. However, the effects of photography on the patient are likely to be similar to those on patients with CAIS and in these extremely sensitive situations the value of any photography must be carefully evaluated.

Psychological impact of photography on the patient

"They made me be naked in a room and take pictures of me and they took pieces of my skin and left two marks one on each arm and nobody said to me why they were doing it. Those marks are still there, and I look at them and I think "Why did they do that?" You know, why did they make me stand in a room and have pictures taken with no clothes on and humiliate me like that without saying anything to me. Why, what was wrong with me?" A 53-year-old-with CAIS.

When this patient talked about having had clinical photographs taken in her early teens she had tears in her eyes and she was angry. She has skin biopsy scars to



Fig. 1. This picture was provided by a 36-year-old with CAIS; it was taken in hospital without her mother's knowledge when she was 3.2 years old.

remind her of the experience that she has been trying to make sense of in the intervening 30 years. The patient asked these questions with imploring urgency. She knows that she has a rare genetic syndrome and suspects that doctors wanted to photograph the stigmata of her condition. In essence, she knows exactly what was 'wrong' with her. What she still finds impossible to reconcile is why she was treated in this way and was made, or was allowed, to feel the way she did.

"I was shocked when I saw it (the picture)- not as shocked as my mom was, though! But we got through it. My mom was holding me when he took the pix, but had no idea he would publish them. She thought he was just taking pictures of me. I kind of like my little picture! I've made a little peace with that tiny child with the sad eyes." (Fig. 2).

The experience of being photographed has exemplified for many people with intersex conditions the powerlessness and humiliation felt during medical investigations and interventions. The lack of consent sought or



Fig. 2. This picture was found by a 40-year-old with CAIS, whilst searching for medical information about her condition.

information given during treatment is often typified by the memory of standing naked against a wall and holding a position for the camera. Similarly, when people search medical texts to look for answers about themselves, they see photographs of themselves or others, learn the clinical facts about their condition, and can at once be taken back to the emotional environment of personal confusion, parental worry and clinician's anxiety. Identification with the pain and distress captured by the photograph means that the affected people feel it afresh.

The question posed by people who have had this experience is; *'How bad am I that someone can make me feel like that?'* This interpretation of the experience of clinical photography is personal and complex. The patient is encouraged to expose the parts of her that she has been told are aberrant. These are documented and presented as her defining features. Despite respectful and caring treatment at other times, there is a risk that the photography process will be perceived as representing the genuine position of the clinician. The patient assumes that her painful emotional responses are known and accepted by the clinician. This leads her to conclude that she must be worth little.

Conclusion

Obtaining images of patients without fully informed consent is unethical and may have serious consequences. All clinical images should be taken after full consent has been obtained and should be maintained in a secure regulated environment to protect patient confidentiality. Whilst intersex patients have specific and unique needs, the principles of minimizing psychological distress from clinical photography apply equally to all patients regardless of their condition.

In intersex patients, undergoing clinical photography causes unnecessary distress and suffering. It can compromise the relationship between patient and doctor and can lead to long-term psychological trauma. Careful consideration should be given to every image request before fully informed consent is obtained, and to minimize the psychological distress all images, where possible, should be obtained whilst under anaesthetic for surgical treatment or investigation. Full-body views of naked intersex patients contravene all the duties of care of doctors, and should neither be taken nor used for education or publication.

To summarize:

- A proportion of medical photography is for publication and presentation and is not essential to the care of any individual patient.
- Medical photography may have significant effects on the patient and their family. This is particularly true of intersex conditions but is likely to apply to other patients.
- Patients undergoing medical photography must be fully informed as to the purpose of the photograph and full consent for each use must be sought.
- Pictures taken by other than photographic staff should be subject to the same storage and use regulations as those taken by the professional photographic staff.
- Photographs of the genitalia and other sensitive areas in children and intersex patients should where possible be taken at the time of general anaesthetic for treatment or investigation.
- Whole-body naked photographs of children or adults with intersex disorders cause serious psychological sequelae and should not be taken. They do not educate or inform and should no longer be used for teaching and publication.
- Further objective work on the long-term influence of medical photography on patients is required.

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Authors

S. Creighton, MD, MRCOG, Consultant Gynaecologist.

J. Alderson, BSc, MSc, DClin Psychol, Chartered Clinical Psychologist.

S. Brown, MSc, FIMI, FBIPP, FBPA, Director of Media Resources. C.L. Minto, MB, ChB, Research Fellow.

Correspondence: S. Creighton, Department of Obstetrics & Gynaecology, University College London Hospitals, UK.

e-mail: sarah.creighton@uclh.org

Abbreviations: GMC, General Medical Council; IMI, Institute of Medical Illustrators; CAIS, complete androgen insensitivity.

Editorial comment

This important paper highlights some, but by no means all, of the issues surrounding the ethics of clinical photographs. Although consent is required before a clinical photograph is taken, there are specific issues which relate to obtaining consent from children that are worth highlighting. For example, at what age are children considered able to give their own consent to the taking of photographs? Are children always told that they can consent or refuse to be photographed or take part in

research? How do you ensure that you respect the rights of children who are perhaps too shy to express their views clearly and if children are not asked for their consent, how is this justified? If consent is given, every effort must be made to reduce possible harm such as intrusion, distress or embarrassment [1,2].

Although these authors have made some useful suggestions with regard to standards for good practice in obtaining medical images, there is currently no way of checking whether these good standards have been carried out. Should police checks be undertaken on all researchers who have significant unsupervised access to children? How does one protect against clinical photographs ending up on pornographic web sites? Should consent be requested from people for all future uses of their photograph? There is nothing to prevent photographs being copied or borrowed. It is standard practice

at some International conferences to copy all slides used, often without the permission of the presenter and without any details provided of what happens to these copies. If clinical images are to be used in presentations, then the patient's express consent should be obtained and submitted to the organisers of the meeting. It should be noted that meetings outside the UK are not subjected to our Data Protection Act.

Gordon Williams
Assistant Editor
Hammersmith Hospital

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