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SYMPOSIUM: THE HISTORY OF THE FIRST IVF BIRTHS

The Oldham Notebooks: an analysis of the development of IVF 1969–1978. IV. Ethical aspects

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Abstract Six evidential sources are examined to investigate how Edwards and Steptoe applied ethical standards to their research leading to the birth of Louise Brown: (i) Their own contemporary writings from 1970 onwards. (ii) Archival evidence from the British Medical Association (BMA), the British Association for the Advancement of Science (BAAS), and correspondence between Edwards and the Ford Foundation. (iii) Minutes of Oldham General Hospital (OGH) Ethics Committee. (iv) Letters by Edwards to prospective patients. (v) oral evidence from interviews with a patient and colleagues. (vi) Evidence from their clinical case management of patients. Taken together these sources suggest that Edwards and Steptoe demonstrated a strong awareness of the ethical issues involved, and offer evidence of honesty to patients about the realistic prospects of success and ethical practice. Nonetheless, decisive evidence that ethical aspirations were put into practice is not available.

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Introduction

Louise Joy Brown was the first child born of an IVF procedure on 25 July 1978 (Steptoe and Edwards, 1978). The recent discovery of research notes from this period amongst the papers of Edwards and at Bourn Hall Clinic has now enabled us to undertake an objective archival-based account of the work that led up to this birth. Our accompanying papers

(Elder and Johnson, 2015a, 2015b, 2015c) describe our archival research on the clinical and scientific aspects of the work. In those papers, we show that the numbers of patients and treatment cycles involved was higher than had been known before (Elder and Johnson, 2015b), and we document the evidence underlying the approaches used to try to resolve the many problems encountered (Elder and Johnson, 2015c). Here we describe our research into the ethical

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aspects of that work which are exclusively the ethics concerning the patients being treated or, at least initially, serving as experimental subjects. Interestingly, at that time, the ethics of researching on human embryos did not feature much, only coming to the fore in the 1980s (Johnson and Theodosiou, 2012; Johnson et al., 2010).

Materials and methods

The data were abstracted from notebooks and loose paper sheets and scraps, anonymised and analysed as described in Elder and Johnson (2015a), which also describes the archival sources used. Briefly, these include archives at the British Medical Association (BMA) and at the National Archive (NA) plus papers among the possessions of the late Edwards and his late wife, Ruth Fowler Edwards, which have been kindly made available to us by his family (RGE). In-text references are indicated by the archive initials plus a reference number and date, and the details for each reference are recorded in the reference list. In addition, scientific papers and the volume *A Matter of Life* (Edwards and Steptoe, 1980) have been consulted, as described in Elder and Johnson (2015a).

We have interviewed patient Grace McDonald [GM], who volunteered to be interviewed (for transcript see Suppl. Material 1 in Elder and Johnson, 2015b). We felt constrained from approaching other patients by issues of sensitivity and confidentiality; indirect soundings elicited concerns about public exposure, and were therefore not pursued. We have also interviewed three members of staff who were associated with the research in Oldham. We jointly interviewed in person John Webster [JW] and Noni Fallows [NF], and one of us [MHJ]

interviewed Sandra Corbett [SC] by telephone (Figure 1). Edited transcripts of these interviews are available (Suppl. Materials 1 and 2), and are referenced by the initials JW, NF or SC followed by the page number(s) referred to. Each of these interviewees has consented to the use in this paper of all information that refers to their transcripts.

Results and discussion

The data in Elder and Johnson (2015b) make it clear that up to 282 patients were exposed to 457 laparoscopic cycles to produce two live healthy babies. The Medical Research Council (MRC), in declining to fund this work in 1971, cited ethical concerns as major reasons for their decision, in particular the need for more animal and primate research, and concerns about the use of women for “purely experimental purposes” (Johnson et al., 2010). Here we review the evidence that bears on the question: how did Edwards and Steptoe attempt to address the ethical issues confronting them? We have examined six sources of evidence in an attempt to address this question.

Publications by Edwards and Steptoe

Relatively few primary papers from Steptoe and Edwards discuss consent procedures (as was the norm in that period; see Beecher, 1966), but some do. For example, Steptoe and Edwards (1970, p.683) state that they “insisted that all of them [“the volunteer patients”] were referred to us in the normal way through normal medical channels”, and confirmatory evidence of referral by a range of doctors is found in



Figure 1 Nursing staff with Patrick Steptoe at Oldham General Hospital, July 1978: (left to right, front row) Edith Astall, Sandra Corbett, Noni Fallows, Sandra Marr, Marjorie Travis, Muriel Harris; (back row) Lorna Jones, Jennifer Thompson, Olga Brewster (Copyright John Fallows Collection, reproduced with permission).

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