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COMMENTARY

Honouring 'Patient 38' — a mother of all IVF mothers?

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Abstract This commentary addresses one aspect of the early history of IVF in Britain. Specific data are re-examined from the recently published, anonymized database of medical records from the Oldham period of research conducted by Robert Edwards, Patrick Steptoe and their team of assistants between 1969 and 1978. By focusing on a reformulation of the 'scheduled treatment cycles per patient', attention is drawn to the small, but nevertheless not insignificant, number of subjects who returned to Oldham at least five times or more to undergo innovative procedures and/or receive other experimental treatments over the duration of the research project. These multiple efforts are contrasted with the single or double treatment cycles received by the majority of the infertile women involved, including the only two experiencing live births, Lesley Brown and Grace Montgomery. The re-presented data facilitates new interpretations and raises fresh research questions about the nature of contemporary and present characterisations of the major protagonists in the 'IVF story', the identity of those women who originally took part and the origin of and reasons for discrepancies in the records maintained about research subjects.

KEYWORDS: history of IVF, human experimentation

Between 1969 and 1978, Robert Edwards, Jean Purdy, Patrick Steptoe and their team of NHS doctors and nurses in Oldham, Lancashire worked determinedly to bring about the first extracorporeal insemination of a human ovum, and subsequently the first live birth after in-vitro fertilisation. Clearly, they were pioneers in their field, heroically persisting despite awkward practical arrangements, and working for what they described as many inconvenient hours in an experimental programme (Johnson and Elder, 2015a p. 39) to reach a goal that some professional contemporaries said was either impossible or unethical. For this, and other subsequent work, many professional awards and honours were granted to both men, including a Nobel prize for Edwards; tributes to their resolve and ingenuity.

The first individual to have fully benefitted from this work, Lesley Brown, has also been similarly lionized in popular culture, as a 'stoical' and dogged woman who sacrificed much and never gave up, consequently rewarded for her special tenacity with the first test-tube baby in the world. Although it has subsequently become clear that Lesley herself never believed she was anything other than an 'ordinary' woman, on the eve of her delivery, the *Daily Mail* nevertheless reported:

> Her willingness to subject her body … to pain, to the knife, to any known, or as yet unknown, technique which would make her a mother was unlimited … She was set to make any sacrifice, seize any hope, take any chance. … We'd do well to remember

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> that medical history is being made because of the fanatical courageous determination of a woman who was so obsessive about bearing and loving her own child that she persisted relentlessly in her quest (Potter, 1978).

Yet, in the 40th anniversary year of this momentous event, we should perhaps remember the other 281 women who sacrificed just as much, if not more, during the Oldham research programme (let alone similar hundreds in other cities and countries worldwide). These women were Steptoe and Edwards's other female research subjects who can only have experienced embodied loss as the international celebrations unfolded around them. They were similarly brave, persistent and resolute, and equally were pioneers in the face of what were then, as perceived at the time, entirely experimental treatments. Only one other woman from the period of research (0.4% of the remaining 281 women) Grace Montgomery, experienced a successful live birth. The whole cohort experienced 3 live births (1.1%, 3/282) but only 2 children (0.7%, 2/282).

Details of the procedures these women underwent have recently been documented in a series of articles and an anonymised database published in this journal (Elder and Johnson, 2015a, 2015b, 2015c, 2015d; Johnson and Elder, 2015a, 2015b, 2015c). An impressive *tour-de-force* of scholarship, the database and its companion publications provide a fascinating, detailed insight into the progress of pathbreaking original research. This enables a more accurate assessment of drug and surgical interventions than hitherto available in the academic record, including cycles of laparoscopic oocyte retrievals, eggs recovered, inseminations, embryos and embryo transfers. Furthermore, amongst other data, 'the number of scheduled treatment cycles per patient' and clinical outcomes are quantified in a smaller table, allowing an analysis of how the burden was shared across the whole sample of infertile women (Elder and Johnson 2015b, Table 2, p. 11).

In Table 1 we present a reformulated tabulation based on Elder and Johnson (2015c) which moves beyond their enumeration of the number of times adult females 'gave of themselves' as counts in categories denoting a technical process. Re-presenting certain data in our new way permits other interpretations and perspectives on outcomes to be created: (i) increasing visibility of individual women, (ii) focusing on particular women who contributed repeatedly, and (iii) identifying discrepancies and inconsistencies in data recording or transcription.

In relation to the visibility of individuals, whilst for the most part the Oldham women still remain anonymous, detailed historical research has revealed that several can potentially be identified by name, former address and sometimes a picture from contemporary records freely available in the public

Table 1 Women (referred to as 'patients') who collaborated multiple times during the Oldham experimental period, 1969–1978.

Patient identity number	Age at first and last treatment cycle (years)		Number of laparoscopic oocyte retrievals	Dates of laparoscopic oocyte retrieval [recorded age in years] and clinical outcomes (biochemical and clinical pregnancies)
9	35	37	5	5 April 1969 [35]; 14 August 1969 [35]; 21 November 1969 (first fertilization *in vitro*) [34[a]]; 2 February 1970 [35]; 20 January 1972 [37]
28	33	40	9	4 July 1969 [33]; 27 April 1970 [34]; 23 September 1971 [35]; 1 May 1972 [38[a]], 31 May 1974 [40[a]]; 26 April 1975 [40[a]]; 19 June 1975 [40]; 18 March 1976 [40]; 11 September 1976 [40]
38	29	38[a]	10	6 October 1969 [29]; 17 August 1970 [30]; 12 January 1973 [32]; 6 December 1973 [33]; 19 June 1975 [35] (pregnancy established until 14 August, ectopic); 15 December 1975 [35]; 21 February 1977 [36]; 26 February 1978 [37]; 20 May 1978 [38]; 18 July 1978 [37[a]]
44	32	37[a]	7	12 November 1969 [32]; 2 February 1970 [31[a]]; 15 May 1970 [31[a]]; 7 September 1971 [32]; 20 February 1973 [36]; 11 March 1974 [37]; 28 May 1974 [36[a]]
52	25	28	6	12 January 1970 [25]; 7 April 1970 [26]; 2 July 1970 [26]; 28 September 1970 [26]; 29 September 1971 [27]; 17 January 1972 [28]
57	27	34	5	3 March 1970 [27]; 13 August 1970 [24[a]]; 16 March 1972 [25[a]]; 3 September 1976 [34]; 10 December 1976 [34]
69	32	37	5	2 July 1970 [32]; 25 January 1971 [33[a]]; 16 March 1972 [33]; 28 June 1975 [38[a]]; July/August 1976 (cancelled) [37]
92	33[a]	40	5	16 June 1971 [33[a]]; 19 January 1972 [35]; 2 April 1973 [36]; 31 May 1973 [36]; 18 June 1976 [40]
110	29	35	6	17 January 1972 [29]; 21 July 1972 [29]; 1 February 1973 [30]; April 1973 [NR] CTI; 7 December 1973 [30]; 24 February 1978 [35]
114	34[a]	36	7	26 April 1972 (GIFT) [34[a]]; 30 January 1973 (sperm + egg to oviduct – GIFT) [34[a]]; April/May 1973 (CTI) [33]; 13 December 1973 [33]; 30 March 1974 [34]; 16 March 1975 [35]; 1 July 1975 [36]
135	35	37	5	21 July 1973 [35]; 9 May 1974 [36]; 29 June 1975 [37]; 3 September 1975 [37]; 28 March 1976 [37]

CTI = Clomid + timed intercourse; GIFT = gamete intrafallopian transfer; NR = not recorded.
[a] Age discrepancy or inconsistency recorded.

domain. This is because the stories of various women were frequently featured in local, national and international media during and beyond the period of research.

The sustained efforts of specific women who repeatedly contributed to the Oldham programme are brought into focus. The anonymised database reveals that several collaborated with Steptoe and Edwards over a long period of time, possibly in the face of extreme adversity: 'patients' 9, 28, 38, 44, 52, 57, 69, 92, 110, 114 and 135. In particular, our attention is drawn to one woman, numbered 38, who appears to have made the greatest contribution to the team's work. She returned ten times between her 29th and 38th birthdays, from the beginning of the research programme in winter 1969 until its close in summer 1978. This contribution was sustained despite continual failure and one (ectopic) pregnancy. The personal inconvenience and sacrifice this may have entailed could be construed as at least equivalent to that made by those professionals who worked on her behalf. Her effort contrasts with the (also great) effort of the majority of subjects; 82% of women completed only one or two laparoscopic oocyte recoveries. 'Patient 38' appears to have been a generous and determined participant in the research programme: a well-motivated patient of Mr. Steptoe and, initially at least until December 1971 when embryo transfers back into patients' bodies began to be conducted, a volunteer for Dr. Edwards' experimental laboratory work; in one sense, in our opinion, 'a mother of all IVF mothers'. Surely, she must be regarded as another heroine in the story of the race to control conception? Lesley Brown was also lucky, as her husband John later admitted, undertaking only a single treatment cycle later in the series in November 1977 (Brown, 1998). The happy outcome for the Browns, and many other IVF parents since, was no doubt a result of lessons learnt from the earlier commitments of research subjects who reaped no immediate benefit at all at the time.

Finally, constructing Table 1 unexpectedly highlighted apparent multiple discrepancies in data recording in relation to the subjects' reported ages: 73% of this case series of eleven women contain one or more. The minimum number of possible age inconsistencies is reported, but without knowing the dates of birth, it is not clear which records are discrepant. It was also difficult to identify the unique patient number of the second woman, reported to have had six treatment cycles, as the cycles were mis-numbered; and the dates of both the live births were inaccurate (now corrected, see Elder and Johnson, 2018).

These disparities raise interesting questions about (a) the contemporaneous context in which the original research was conducted and recorded and (b) the nature and interpretation of the historical sources upon which the larger Elder-Johnson database is built. These would benefit from further clarification. Were 'inconsistencies' in this parameter simply 'just the way it was' at the time; the result of deliberately inaccurate information provided by female patients themselves to hide their 'true age'; the consequence of an overburdened and stressful clinical workload within the NHS such that records were made 'on the run'; or do they indicate poor record-keeping? The anomalies might simply reflect characteristics of the source material itself; the published database presents digitised data originating in patchily-preserved, sometimes incomplete surgical and scientific papers that cannot be cross-referenced owing to the regrettable loss of fully-comprehensive clinical notes which would have been available to the team at the time (Elder and Johnson 2015a, p. 7).

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