European Journal of Obstetrics & Gynecology and Reproductive Biology 238 (2019) 170–177

Contents lists available at ScienceDirect

European Journal of Obstetrics & Gynecology and Reproductive Biology

journal homepage: www.elsevier.com/locate/ejogrb

Review article

Abuse in assisted reproductive technology: A systematic qualitative review and typology

Nathan Hodson[a,*], Susan Bewley[b]

[a] Leicester, UK, College of Life Sciences, University of Leicester, Lancaster Road, Leicester, United Kingdom
[b] London, UK, Department of Women and Children's Health, School of Life Course Sciences, King's College London, United Kingdom

ARTICLE INFO

Article history:
Received 20 March 2019
Received in revised form 18 May 2019
Accepted 23 May 2019

Keywords:
Abuse
Law
Assisted reproductive technology
Systematic review
Qualitative evidence synthesis

ABSTRACT

Objectives: Abuse of vulnerable patients exists in many healthcare settings and has been recognised as an inherent risk in assisted reproductive technology (ART). Systematic reviews have been used to develop typologies of abuse and ethical issues in other settings including obstetrics. The aim was to determine the full spectrum of abuse that patients can experience when using assisted reproductive technology.
Study Design: A systematic qualitative review. MEDLINE, CINAHL, and PsycINFO were searched for combinations of terms related to abuse and terms relating to ART. The last search was performed on February 12th 2018. Selection criteria were that the authors reported evidence of abuse. There were no exclusions by date, language or methodology. Papers lacking analysis of abuses in ART were excluded. For data collection and analysis, themes identified in the academic literature were coded using thematic qualitative analysis by two independent researchers. Themes were developed discursively.
Results: There were 381 publications of which 44 full text articles were screened. The 34 included papers detailed abuses from 4 decades and 5 continents. There were no quantitative papers measuring prevalence. The resulting coding framework was presented as a typology of abuse in assisted reproductive technology with three first order themes: exploitation of class-based vulnerabilities, excessive intervention, and failures of aftercare.
Conclusions: A wide range of categories of abuse was found despite the paucity of formal literature. A concerted public health approach to infertility is required, combined with an emphasis on trying conservative approaches first. More primary research is required on prevalence of abuse, and values and preferences, particularly in "egg sharing" and post-mortem reproduction.

Contents

* Corresponding author.
E-mail address: Nh227@le.ac.uk (N. Hodson).

https://doi.org/10.1016/j.ejogrb.2019.05.027
0301-2115/

Introduction

The growth of assisted reproductive technology (ART) has been described as "among the greatest achievements of medicine in the 20th century" [1]. The first IVF birth gave new hope to people with unwanted infertility. There have been well over one million IVF attempts in the UK alone since. The total number of attempts, success and safety all continue to increase [2].

The conjunction of changing technology with reproduction and relationships requires a continued focus on high medical, and ethical, standards. Abuse and violence are commonplace in many women's lives [3], and are also a rare, but serious, adverse outcome of medical endeavour, inflicting physical and mental harm. As with other medical interventions, there exists both egregious criminal abuse (e.g. doctors using their own gametes [4]) and more subtle and complex wrongs (e.g. financial and emotional pressures). ART can hurt the very people that researchers and clinicians wish to help. Ramifications extend beyond immediate individual harm; past patients are stigmatized, future patients are put off treatment, and trust in professionals falls. All healthcare encounters contain the potential and risk of abuse, so awareness is required [5]. This systematic qualitative review aims to determine systematically the full spectrum of abuse that patients can experience when using assisted reproductive technology.

Systematic reviews of diverse literatures have been effectively used to map abuse in obstetrics [6] and other ethical issues [7,8] and can help providers and policymakers consider human rights effects of policy. However, definitions of abuse vary. In childbirth, Freedman et al. [5] suggest, abuse is anything "experienced as or intended to be humiliating or undignified" or deemed that way by "local consensus". Hale and Vasquez[8] [9] defined abuse of women living with HIV as ; "any act, structure or process in which power is used in such a way as to cause physical, sexual, psychological, financial or legal harm". The wider literature around exploitation, violence and abuse reveals that abused individuals often struggle to identify the way they have been treated as abusive [10].

There have been no previous systematic reviews of abuse in ART.

Methods

For this qualitative evidence synthesis the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement [11] and Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) Statement [12] were both used. This study received no funding.

Search strategy and data sources

Following scoping and piloting to hone search terms, the published literature was systematically searched in MEDLINE, CINAHL, and PsycINFO using controlled vocabulary combining two main components: 1) a form of assisted reproductive technology ("assisted reproductive technology", "infertility", "ovulation induction", "cryopreservation", or "fertility preservation"), and 2) a critique in terms of abuse ("abuse", "crime", "violence", or "exploitation") (See Appendix S1).

Searches were conducted on February 12th 2018. Papers between 1970 and February 12th 2018 were included

Inclusion and exclusion criteria

Publications were included if they discussed ART in terms of abuse. Eligible papers studied women and/or men undergoing ART treatments. No control was required. Outcomes pertained to the naming or perception of abuse. ART was defined however the term was used in the retrieved results. Similarly, no single definition of abuse was used but authors' use of keywords was initially taken at face value. Papers were included if they used philosophical-ethical or empirical methodologies, related technology to interpersonal dimensions, and focussed on medical treatment. Publications from journals, books, reports, magazines and newspapers were all subject to the same inclusion criteria. There were no exclusions by date of publication, language or methodological or theoretical quality. Papers which denied the existence of abuses were excluded as the aim was to map known abuse rather than debate its extent. Papers whose only focus was on questions of the moral status of the embryo and the rights of individuals to use their gametes were excluded. A decision was made to exclude papers which solely addressed intimate partner violence or the exploitation of surrogate mothers as these are already well-studied fields.

Study selection

Search results were imported into RefWorks and duplicates deleted. Screening by title and abstract was performed by both authors according to inclusion criteria. Discrepancies were resolved by discussion. Full texts of eligible publications were obtained. Reasons for all exclusions are shown in Appendix S2.

Data analysis and synthesis

An adapted version of qualitative content analysis, drawing on McLennan et al. [8] was used for data analysis. The framework presented here with first, second, and third order themes was developed inductively from the included papers. Both authors read and coded the first twelve articles selected in order to identify as many abuses as possible. The remaining publications were analysed only by NH. Duplicate analysis also provided interauthor validation. Third-order themes were identified inductively, and then second and first-order themes were drawn out subsequently. Preliminary frameworks were honed through an iterative process whereby authors developed new categories whenever new data could not be accounted for by previous frameworks. Categories

were merged and nested through a discursive process until both authors agreed upon the final matrix of abuses. No quality assessment or risk of bias determination was made anticipating the wide variety of different designs.

Results

General overview

The literature search identified 381 publications of which 44 full text articles were obtained and 34 included (28 journal articles, 1 newspaper article, 2 magazine articles, 1 official report, 1 organisation bulletin, and 1 court case) (Table 1). The earliest publication was from 1987, with 8 from the 1990s, 12 from the 2000s, and 12 from the 2010s. There was some global representation as evidence came from 5 continents, though research was overwhelmingly conducted from high income countries (USA/Canada 12, UK 9, 2 each from Israel, Italy, Singapore, and The Netherlands, and 1 each from India, Belgium, Spain, Sweden, and Nigeria) and only one paper required translation from Swedish [33]. The publications took different forms; 10 presented results from primary research, 12 presented original legal or ethical research, 6 were systematic reviews or reviews, and 6 other methodologies. Seven manuscripts acknowledged external funding (from the European Commission, The Canadian Health Ministry, London Women's Clinic, the UK Medical Research Council, UN Population Fund, Soros Foundation, Ford Foundation, and a variety of Canadian University and research council grants). The design and funding of each publication are summarised in Table 1.

Prevalence

No primary study investigating the prevalence of abuse was found.

Types of abuse

There were 31 third-order descriptive themes and 8 second-order themes identified. The full typology of abuses in ART is presented in Table 2 [13–46].

List of 3rd order themes

The third order themes were as follows: Made responsible for fertility, use of biological resources, pressure to be have multiple children, competing health and social values, discriminatory exclusion, sex-selective procedures, hormonal experimentation, post-mortem sperm extraction, use of frozen embryos, dishonesty about implications of sperm donation, challenges for women from ethnic minorities, exploitation of lesbian couples, ageism and exploitation of perimenopausal women, exclusion due to HIV, financial abuse, inadequate preventative effort, inadequate alternatives offered, unethical research and fraud, poor quality research, misuse of language around research, false hopes, overpromising about results, withholding add-ons, avoidable health risks to child, withholding knowledge of father, abuse or exploitation after birth, division after intra-familial donation, fear of rejection after extra-familial donation, dealing with having acted against ones convictions, loss of contact with people with embryos in storage, failure to collect data on research participants

Exploitation of class-based vulnerabilities

This largely comprises abuses that arise before ART, particularly relating to the place of women within their family and wider society. Abuses where vulnerabilities intersect were identified. Men were also found to be susceptible to a loss of control over their fertility within the context of ART.

Abuse of women within the family. Families often put pressure on women to use ART [13,14]. Women were often held responsible for a couple's fertility and the possibility of male factor infertility was sometimes understated [15]. The pressure to continue the family line could result in pressure to use the sperm of a deceased partner [16]. Women faced pressure to use their reproductive biology to produce another generation. This impacts the closest family relationships (daughter-to-mother egg donation makes it particularly difficult to establish true consent) [17] and doctor-patient relationships (the pressure to participate in "egg-sharing" programmes in order to maintain good relations with doctors particularly impacts women) [18]. The stigma surrounding fetal reduction is another form of pressure to adhere to an idealised role of motherhood, especially within the high-risk context of ART [19]. Although the pressure behind these abuses predominantly comes from the family, one early paper suggested that where clinics facilitate these practices they assume complicity in the abuse [20].

Abuse of women by society. Another group of abuses against women originate outside the family. Comparisons were drawn between the safety evidence for clomifene and previous hormone therapies used by women such as diethylstilboestrol [21]. Others drew attention to the potential conflict between the health and social factors of the child, arguing that women taking into account non-health factors faced harsh criticism [22,23]. One clinic worker's visceral reaction to mothers' choices was reported: "they use donors with an adoptive parent which just makes me want to vomit" [23]. The standards women seeking to use ART are held to are suggested as unfair [20], and the use of ART to facilitate sex selection was another intersection of ART and sex inequality [19,20].

Abuse of men's consent. The abuse of men was characterised by the axiom that male control over reproduction ends at ejaculation, [24] with a suggestion that sperm banks' casual portrayal of donation is incongruent with the serious nature of donation and amounts to manipulation [17]. The implantation of frozen embryos against the father's wishes extended this principle. However it was post-mortem sperm extraction that represents the most significant abuse of men's reproductive autonomy [25,16].

Perpetuation and exploitation of other classes of social vulnerabilities. Aside from sex, abuses were identified along lines of race, [20] immigrant background [13], age [17], sexuality [26], religion [20], and HIV status [17]. These involved both unfair exclusion from ART [17,20,27] and unreasonable pressure to use ART [13,26]. Although the finding has been downplayed [26] it has been demonstrated that "egg sharing" programmes entail a net flow of healthy eggs from young lesbians to older, richer, heterosexual couples. Financial abuses intersect with each of these [37,44]. Couples are trapped by upfront payments [23] and many are encouraged to exhaust their savings on expensive interventions as the likelihood of success dwindles [34,33,4].

Excessive intervention

This characterises abuses taking place during ART, specifically unnecessary and/or ineffective procedures.

Abuses leading to unnecessary procedures. A major theme across the literature was the absence of a concerted public health campaign regarding infertility, leading to couples using ART without first trying conservative measures [15,20,26,27,46,45]. Nor were alternative ways to start a family, such as intrauterine insemination [46] or even adoption [20], sufficiently promoted.

Table 1
Included papers: Table 1 outlines the methodology, content, and provenance of all papers included in the review.

First Author(s), Country, Year	Title (reference number)	Methodology	Funding
British Columbia Centre of Excellence for Women's Health, Canada, 2002	From floods to infertility: new research from the centres of excellence for women' health [22]	Authoethnography of a queer woman doing research on queer women	Funded (i)
Beeson D, USA / Canada, 2006	Egg harvesting for stem cell research: medical risks and ethical problems [21]	Review	No funding
Benagiano G, Italy, 2003	Public health policy and infertility [27]	Ethical argument	Not declared
Blackwell RE, USA,1987	Are we exploiting the infertile couple? [39]	Reflection of practitioners	No funding
Blythe E, UK, 2008	Inequalities in reproductive health: what is the challenge for social work and how can it respond? [32]	Review	Not declared
Bourg C, Belgium, 2015	Ethical dilemmas in medically assisted procreation: a psychological perspective [45]	Reports of clinical experience	Not declared
Campagne DM, Spain, 2013	Can male infertility be improved prior to assisted reproduction through the control of uncommonly considered factors? [15]	Systematic review	Not declared
Catron J, USA, 2014	Ethics on the ground: egg donor agency behaviour in an unregulated legal environment and the growth of ethical norms in a new field. [23]	Semi-structured interviews with egg donor agency workers	Not declared
Chandra HS, India, 1997	The new genetics and ethics: sixth Shri BV Narayana Reddy memorial lecture [19]	Ethical argument	Not declared
Charles S, USA, 2002	Mothers in the media blamed and celebrated - an examination of drug abuse and multiple births [28]	Lexis Nexis searches	Not declared
Cooper S, UK, 1997	Ethical issues associated with the new reproductive technologies [17]	Review	Not declared
Evans D, UK, 1996	Fertility, infertility and the human embryo: ethics, law and practice of human artificial procreation [24]	Review	Funded (ii)
Evers JL, Netherlands, 2013	The wobbly evidence base of reproductive medicine [40]	Ethical argument	No funding
Forman R, UK, 2011	Cross-border reproductive care: A clinician's perspective. [30]	Editorial	Not declared (iii)
Gurtin ZB, UK, 2012	Egg-sharing, consent and exploitation: examining donors and recipients circumstances and retrospective reflections [26]	Questionnaire research with 124 donors and 122 recipients	Funded (iv)
Haimes E, UK, 2012	Eggs, ethics and exploitation? investigating women's experiences of an egg sharing scheme [46]	Interviews with donors	Funded (v)
Harwood K, USA, 2009	Egg freezing: a breakthrough for reproductive autonomy? [38]	Interviews with providers	No funding
Heng BC, Singapore, 2007	Discarded human spermatozoa, eggs and embryos for personnel training and practice in assisted reproduction [31]	Ethical argument	Not declared
Heng BC, Singapore, 2006	Ethical issues in transnational "mail order" oocyte donation [43]	Ethical argument	No funding
Kol S, Israel, 2005	Society's contribution to assisted reproductive technology abuse [25]	Correspondence, opinion	Not declared
Landau R, Israel, 2004	Posthumous sperm retrieval for the purpose of later insemination or IVF in Israel: an ethical and psychosocial critique [16]	Legal argument	Not declared
Makinde OA, Nigeria, 2017	Baby factories in Nigeria: Starting the discussion towards a national prevention policy. [37]	Review	Not funded
McCormack T, Canada, 1988	Public policies and reproductive technology: a feminist critique [20]	Ethical argument from radical feminist perspective	Not declared
Miller A, USA, 1992	Baby makers inc.[34]	Newspaper report	Not declared
Nahman M, UK, 2011	Reverse traffic: intersecting inequalities in human egg donation [41]	Interviews with donors	Funded (vi)
Nap AW, Netherlands, 2007	Couples with infertility belong to a very vulnerable group, they should not be exploited. [42]	Ethical argument	No funding
Neri M, Italy, 2016	Egg Production and Donation: A New Frontier in the Global Landscape of Cross-Border Reproductive Care [14]	Ethical argument	Not declared
Nilsson L, Sweden, 1995	Ovarian stimulation. use and "abuse" [33]	Ethical argument	Not declared
Ramskold LAH, UK, 2013	Commercial surrogacy: How provisions of monetary remuneration and powers of international law can prevent exploitation of gestational surrogates. [44]	Ethical and legal argument	Not declared
Shanner L, USA, 1995	Abuse by medical practice? Clinical reinforcement of negative cultural norms [13]	Ethical argument	Not declared
Smith E, Canada, 2010	Reproductive tourism in Argentina: Clinic accreditation and its implications for consumers, health professionals and policy makers. [36]	Primary research in Latin American fertility clinics	Funded (vii)
Weiss R, USA, 1998	Fertility innovation or exploitation [18]	Journalism	Washington Post
Widge A, UK, 2009	ART in India: The views of practitioners [35]	Postal questionnaire	Funded (viii)
Not applicable, USA, 1997	Huddleston v. Infertility Center of America [29]	Court case	Court case

i) Women's Health Contribution Program (WHCP) discontinued 2013 – Canadian Minister for Health
ii) This paper presents the key elements of the Final Report to the European Commission from a Concerted Action (BMH1-CT92–1276) sponsored under the Commission's BIOMED programme
iii) Author stated he is Medical Director of an Assisted Conception Clinic
iv) This study was funded by a research grant from the London Women's Clinic to the Centre for Family Research, University of Cambridge
v) This research was funded by the UK Medical Research Council (G0,701,109).
vi) Wenner-Gren Foundation Dissertation Fieldwork Grant and Social Science and Humanities Research Council of *Canada* Fellowship
vii) ES was supported by a COPSE studentship from the Faculty of Medicine (Université de Montréal), CM by a Bioethics scholarship from the Faculty of Graduate Studies (Université de Montréal), and JB by scholarships from the Fonds de la recherche en santé du Québec (FRSQ), the Université de Montréal and the APOGEE-Net Network of *Canada*. This project, part of larger program of research, was supported by grants to Bryn Williams-Jones from the Faculty of Medicine of the Université de Montréal (start-up grant, 2006), the Social Sciences and Humanities Research Council of *Canada* (SSHRC Institutional pilot grant, 2007), and the International Institute of Research in Ethics and Biomedicine (IIREB travel award to visit Argentina, 2008)
viii) Ford foundation, UNFPA, Soros Foundation, and FOGSI (Federal Obstetric and Gynaecological Societies of India)

Table 2
Typology. This table shows a typology of abuses in assisted reproductive technology.

1st order themes	2nd order themes	3rd order themes
Exploiting class-based vulnerabilities	Abuse of women within family	Made responsible for fertility
		Use of biological resources
		Pressure to be a have multiple children
	Abuse of women by society	Competing health and social values
		Discriminatory exclusion
		Sex-selective procedures
		Hormonal experimentation
	Abuse of men's consent	Post-mortem sperm extraction
		Use of frozen embryos
		Dishonesty about implications of sperm donation
	Intersection with other disadvantages	Challenges for women from ethnic minorities
		Exploitation of lesbian couples
		Ageism and exploitation of perimenopausal women
		Exclusion due to HIV
		Financial abuse
Excessive intervention	Unnecessary procedures	Inadequate preventative effort
		Inadequate alternatives offered
		Unethical research and fraud
	Ineffective procedures	Poor quality research
		Misuse of language around research
		False hopes
		Overpromising about results
		Withholding add-ons
Failure of aftercare	Avoidable harm to offspring	Avoidable health risks to child
		Withholding knowledge of father
		Abuse or exploitation after birth
	Avoidable harm to participants	Division after intra-familial donation
		Fear of rejection after extra-familial donation
		Dealing with having acted against ones convictions
	Failures of data management	Loss of contact with people with embryos in storage
		Failure to collect data on research participants

The other reason for unnecessary procedures was research marred by conflicts of interest, [21] including extreme cases such as Hwang's coercively obtained materials and falsified results [21] and cases where women received mixed messaging about the likelihood of a clinically applicable results and allowing them to participate in research under the illusion that new treatments were imminent [18,20,21].

Abuses leading to ineffective procedures. This connected category was characterised by dishonesty about the potential of poor quality treatment, summed up as "in reproductive medicine, false hopes are the great untallied commodity" [18]. Underlying this phenomenon is the often low quality, retrospective [21], ill-defined [20], research. However poorly supported, interventions may continue due to inaccurate use of language in their description [17,21,46] and instances of raising false hopes and overpromising [21,23]. One clinic worker described delayed introduction of add-ons (unproven adjuncts to treatment intended to increase likelihood of a successful treatment) only as abusive in the context of multiple failed rounds of IVF without add-ons [23].

Failure of aftercare

This describes abuse manifested after successful or unsuccessful ART. Many related to conflict within the family and inept data management by clinics. However the unnecessary adversity facing children created through ART was another important dimension.

Avoidable harm to offspring. Clinic workers identified abuse in unnecessarily exposing offspring to health risks, whether this involved excluding adopted people from gamete donation or balances around multiple pregnancy [23,28]. Paternal relationships were particularly contentious, whether children were denied knowledge of their father due to anonymity [17,27,45], implanted into a uterus after the death of their father [16,24] or exposed to specific disadvantages relating to inheritance and marriageability [16]. The explicit harm to offspring arose where children were created through ART with the intention of exploitation as a carer [24] and physical abuse [29].

Avoidable harm to patients. Abuses derived from avoidable harm to patients did not include unavoidable side-effects, perhaps because these cannot be described as abuses, but included issues relating to family relationships and personal morality. Some people who act as donors or surrogates for relatives discover that they experience intense emotional connections which become a source of shame and pain – an abuse in contexts where professionals have failed to offer warning or preparation [17]. Conversely, donation from outside the family can engender anxiety, secrecy and fear of rejection, interpreted by one author as inserting "a lie at the centre of the most basic of relationships" [17]. Others are encouraged to make donations against their convictions and left to handle the moral tension without support [17,16]. Exposing women to infectious diseases emerged as an important historical abuse [16,24,29].

Failures of data management. Under certain circumstances poor record-keeping could amount to abusive practice, particularly in relation to poor quality research and flawed national monitoring of such research [18] as well as the failure to plan for research and training [31] or the eventuality of parents abandoning their embryos [24].

Discussion

Main findings

This typology reveals a wide range of abuses related to many different stakeholders, some directly perpetrated by professionals. These abuses related to exploitation of pre-existing class-based vulnerabilities, over-intervention, and poor aftercare. Overall, however, there is scarce research into ART-related abuse, and no documentation of its extent. Most research used non-empirical methodologies, emphasising case studies and vignettes.

Interpretation (in light of other evidence)

It is arguable whether all the themes collated here amount to abuse given that abuse has not been formally defined within the ART context; this only represents what has been published. There may be more unpublished instances of interpersonal, healthcare provider or human rights abuses. The novel typology could be adapted as technology advances and further abuses emerge. Abuses identified thus far resemble those in childbirth and HIV [6,9] in that they often involve structures and processes. This review has found adverse effects of this misuse of power including physical, financial, and psychological harms, but adds more nuance by including issues relating to identity, particularly consent to fatherhood and knowledge of one's paternity.

Generating a typology allows future formal appraisal [6]. Naturally, some primary research, e.g. Hwang, did not describe itself as intrinsic abuse [47,48]. But the cited reviews identified the abuse within those situations; our typology brings these observations together. It draws attention to contradictions between

themes; abuse of offspring exposed to health risks vs. experience of mothers pressured into prioritising health over important social factors. Similarly, clinics intervening too early vs. delay - both being criticized. Despite excluding papers focussed predominantly upon intimate partner violence our typology includes abuse within the family, perhaps suggesting that coercion into ART within the extended family cannot easily be delineated from other forms of reproductive coercion [49]. In emerging fields, conflicts are no reason for resignation, but the difficulty of navigating different parties' competing claims verifies the World Medical Association's warning: "*Assisted reproductive technology always involves handling and manipulation of human gametes and embryos. Different individuals regard this with different levels of concern but there is general agreement that these special concerns should be met by specific safeguards to protect from abuse.*" [50]. Abuse is always a risk – so closer attention must be paid to identifying and remediating ongoing abuse.

Strengths and Limitations

This first systematic review of abuses in ART, draws on methodology from obstetrics [6], sexual and reproductive health [9], and other systematic reviews of qualitative data. [7,8] The deliberately wide inclusion criteria ensured mapping of all ART-based abuses documented so far in academic literature. Results were included irrespective of date, country of origin, methodology, or language. The variety of countries and methodologies allowed for many perspectives upon related phenomena. However, the small number of articles, scant primary research, and absence of prevalence studies affect reliability. Limitations include a parsimonious search strategy that required authors to describe phenomena as abusive, violent or exploitative thus potentially skewing the literature and meaning that some broadly connected papers were not found by our initial search. [51,52] Findings might represent the severer end of the abuse spectrum, missing human rights concepts, and minimising the extent compared to use of the overarching term "mistreatment" [6]. Despite excluding papers solely addressing intimate partner violence or surrogacy, these two issues still featured strongly in the literature. Time constraints prevented searching all embedded references in papers so findings may be under-representative. For example, one recent study [53] examining exaggerated health claims of non-evidenced based 'add-ons' was not identified. Few papers were excluded at the full-text stage, probably because the abstract clearly indicated that abuse was being studied; this might suggest too stringent exclusion criteria. No formal tools were used to assess bias due to resource limitations, the heterogeneity of study types and paucity of quantitative data.

Implications for clinicians and policy makers

Clinicians, and patients, must be aware of abuse, how to report and counteract it, and what to do within their own clinic or regulatory system. Concerns about consent should prompt examination of the feasibility of donation registers for men who wish to permit post-mortem sperm extraction and use. It is already recognised that self-regulation is insufficient with calls for international conventions to ensure proper procedures in all legislatures [44].

Those abuses arising from futile, unnecessary, or excessively early ART can only be eliminated by enabling people to protect their fertility. Improved public understanding that infertility is treatable may enable people to think ahead, although interventions are difficult. Early advocates recommended a public health approach to infertility [54], but insensitive early campaigning attracted significant backlash [55]. The largely private funding reduces the incentive for healthcare bodies to organise public health campaigns (e.g. prevention of sexually transmitted diseases) or consider the implications of other policies (e.g. trends of older motherhood, increasing use of international surrogacy). Although conservative management involving psycho-social interventions has been encouraged, [56] expectant management requires further research as current knowledge has been described as "very crude" [57].

Several revealed abuses relate to secrecy and conflation of genetic, gestational and social roles of parenting. Empirical studies often conflate moral and psychosocial evidence and the significant internalized stigma leads to anxiety about superficial similarities between donor and recipient and about disclosure [58–62]. Further descriptive research is unlikely to overcome such stigma; families may benefit from a cultural shift towards acceptance of diverse ways of starting a family and support with disclosure [62].

Implications for research

The typology generated needs expansion and verification. Three processes were repeatedly found in the abuse literature: international surrogacy, "egg-sharing", and post-mortem sperm extraction. In order to clarify these, more research is needed into the experiences and preferences of women who gestate surrogate babies in commercial settings, or who "share" their eggs with others but whose own ART is unsuccessful, especially as these latter women hold particularly nuanced opinions [23]. Similar research should address the values and preferences of men regarding post-mortem extraction and use of their sperm by partners. There is scope for more targeted research into specific abuses, including more quantitative and qualitative work on specific ART procedures, across different countries and legal regimes, and the long-term impact on individuals and families. Given the parsimonious search of the academic literature and contrast with media reports, future reviews should use wider search terms. To assess confidence in the results and before applying the findings to policy formulation, tools such as GRADE-CERQual should be used [63]. Research should remain attuned to public consciousness by investigating media reporting of abuses as well as patients' narratives. However, given only six included papers received external funding, the first barrier may be engaging funders.

Conclusions

From this systematic review a typology of ART abuses has been generated which can be amended in future. Recognition and acceptance of the existence of abuse is an important first step towards its elimination. There is an urgent need for primary investigation of abuse and its prevalence. A human rights perspective can lead to the development of specific policies designed to prevent, reduce, and repair abuses affecting social parents, donors, and offspring.

ART researchers and clinicians are highly innovative and ideally placed to implement positive change, albeit financial incentives and unconscious biases might act in the opposite direction to deny, minimise or silence 'bad news' and dissent. Strengthening of medical and ethical standards must be undertaken with the input of all stakeholders, in particular listening to and seeking out the views of those whose experience of ART was disappointing or painful. Mainstream acceptance of infertility as a treatable condition offers new avenues for public health interventions and might mitigate many key abuses. Although some issues are inherent to ART, fighting stigma and supporting honest communication should prevent abuse and promote the flourishing of families of all compositions.

Contribution to authorship

NH and SB contributed equally to conception, planning, and execution of the systematic review. Both authors reviewed papers, were involved in analysis, writing up (first draft by NH) and approved the final version.

Ethics approval was not sought.

Funding

This work received no funding.

Disclosure of Interests

NH has no interests to declare. SB was a member of NICE Fertility Guideline CG138 (2013). She received a consultancy fee from the RAND corporation for reviewing a report on fertility treatments in 3 European countries (2013), and was paid to chair the NICE Fertility Evidence Update (2015)

Acknowledgements

The authors wish to thank Selina Lock for her generous and creative assistance with scoping searches, as well as Lorraine Bacchus for her incisive comments on an earlier version of the manuscript.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.ejogrb.2019.05.027.

References

[1] Hallak J. A call for more responsible use of Assisted Reproductive Technologies (ARTs) in male infertility: the hidden consequences of abuse, lack of andrological investigation and inaction. Transl Androl Urol 2017;6:997–1004.
[2] Fertility treatment 2014-2016 trends and figures. Human Fertilisation & Embryology Authority. London : HFEA; 2018.
[3] World Health Organization. Violence Against Women 2017;11:29.
[4] Smith R. British man 'fathered 600 children' at own fertility clinic s.n.. London: The Telegraph; 2012.
[5] Freedman LP, Ramsey K, Abuya T, Bellows B, Ndwiga C, Warren CE, et al. Defining disrespect and abuse of women in childbirth: a research, policy and rights agenda. Bull World Health Organ 2014;92:915–7.
[6] Bohren MA, Vogel JP, Hunter EC, Lutsiv O, Makh SK, Souza JP, et al. The Mistreatment of Women during Childbirth in Health Facilities Globally: A Mixed-Methods Systematic Review 6, 06 30. PLoS Med 2015;12:e1001847.
[7] Yıldız E. Ethics in nursing: A systematic review of the framework of evidence perspective. Nursing Ethics 2017;01(01) p. 969733017734412.
[8] McLennan S, Kahrass H, Wieschowski S, Strech D, Langhof H. The spectrum of ethical issues in a Learning Health Care System: a systematic qualitative review 30, 04 01. Int J Qual Health Care 2018;01:161–8.
[9] Hale F, Vazquez M, editors. Violence against women living with HIV and AIDS: a background paper. Washington, DC: Development Connections; 2011.
[10] Social Care Institute for Excellence. Types and indicators of abuse. Safeguarding Adults 2015;01:. . [Cited: 11 2018, 24.] [Online] https://www.scie.org.uk/safeguarding/adults/introduction/types-and-indicators-of-abuse.
[11] Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Ann Intern Med 2009;151:264–9.
[12] Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ 11 27. BMC Med Res Methodol 2012;12:181.
[13] Shanner L. Abuse by Medical Practice? Clinical Reinforcement of Negative Cultural Norms s.l.. Monash Bioethics Rev 1995;14:47–57.
[14] Neri M, Turillazzi E, Pascale N, Riezzo I, Pomara C. Egg Production and Donation: A New Frontier in the Global Landscape of Cross-Border Reproductive Care: Ethical Concerns 4. Curr Pharm Biotechnol 2016;17:316–20.
[15] Campagne DM. Can male fertility be improved prior to assisted reproduction through the control of uncommonly considered factors? Int J Fertil Steril 2013;6:214–23.
[16] Landau R. Posthumous sperm retrieval for the purpose of later insemination or IVF in Israel: an ethical and psychosocial critique. Hum Reprod 2004;19:1952–6.
[17] Cooper S, editor. Ethical issues associated with the new reproductive technologies. In: Infertility: Psychological issues and counselling strategies. Oxford, England: John Wiley & Sons; 1997. p. 41–66.
[18] Weiss R. Fertility innovation or exploitation? s.n.. Washington, DC: Washington Post; 1998.
[19] Chandra HS. The new genetics and ethics 7. Indian J Med Ethics 1997;5:.
[20] McCormack T. Public Policies and Reproductive Technology: A Feminist Critique. Can Public Policy 1988;14:361–75.
[21] Beeson D, Lippman A. Egg harvesting for stem cell research: medical risks and ethical problems. Reprod BioMed Online 2006;13:573–9.
[22] From Floods To Infertility: New Research from the Centres of Excellence for Women's Health. British Columbia Centre of Excellence for Women's Health. Vancouver : BCCEWH; 2006.
[23] Catron J. Ethics on the Ground: Egg Donor Agency Behavior in an Unregulated Legal Environment and the Growth of Ethical Norms in a New Field, Dissertations. UC Berkeley Electronic Theses; 2014.
[24] Evans D, Evans M. Fertility, infertility and the human embryo: ethics, law and practice of human artificial procreation. Hum Reprod Update 1996;2:208–24.
[25] Kol S, Itskovitz-Eldor J. Society's contribution to assisted reproductive technology abuse. Hum Reprod 2005;20:2362.
[26] Gurtin ZB, Ahuja KK, Golombok S. Egg-sharing, consent and exploitation: examining donors' and recipients' circumstances and retrospective reflections. Reprod BioMed Online 2012;24:698–708.
[27] Benagiano G, Farris M. Public health policy and infertility. Reprod Biomed Online 2003;7:606–14.
[28] Charles S, Shivas T. Mothers in the media: Blamed and celebrated – an examination of drug abuse and multiple births. Pediatr Nurs 2002;28:142–5.
[29] Huddleston Phyllis A. Administratrix of the Estate of Jonathan Alan Huddleston, and in her own right, Robert Eyer, Esquire, Co-Administrator of the Estate of Jonathan Alan Huddleston, Appellant, v. Infertility Center of America, Inc, Appellee. 1190217, s.l. : Superior Court of Pennsylvania 08 20. 1997.
[30] Forman R. Cross-border reproductive care: A clinician's perspective. Reprod Biomed 2011;23:808–10 Online.
[31] Heng BC. Discarded human spermatozoa, eggs and embryos for personnel training and practice in assisted reproduction. Reprod Biomed 2007;15(Suppl 2)5–6 Online. 2007.
[32] Blyth E. Inequalities in reproductive health. What is the challenge for social work and how can it respond? J Social Work 2008;8:.
[33] Nilsson L, Bergh T, Jeppson S, Wramsby H. Ovulation stimulation. Use and "abuse" 92. Lakartidningen 1995;15:635–7.
[34] Miller A, Friday C, King P. Baby makers inc. Newsweek 1992;119:38–9.
[35] Widge A, Cleland J. Assisted reproductive technologies in India: The views of practitioners. Hum Fertil 2009;12:144–52.
[36] Smith E, Behrmann J, Martin C, Williams-Jones B. Reproductive tourism in Argentina: Clinic accreditation and its implications for consumers, health professionals and policy makers. Dev World Bioethics 2010;10:59–69.
[37] Makinde OA, Olaleye O, Makinde OO, Huntley SS, Brown B. Baby factories in Nigeria: Starting the discussion toward a national prevention policy. Trauma Violence Abuse. 2017;18:98–105.
[38] Harwood K. Egg freezing: a breakthrough for reproductive autonomy? s.n.. Bioethics 2009;23:39–46.
[39] Blackwell RE, Carr BR, Chang RJ, DeCherney AH, Haney AF, Keye Jr WR, et al. Are we exploiting the infertile couple? 5. Fertil Steril 1987;48:735–9.
[40] Evers JL. The wobbly evidence base of reproductive medicine. Reprod Biomed 2013;27:742–6 Online.
[41] Nahman M. Reverse traffic: intersecting inequalities in human egg donation 5. Reprod Biomed Online 2011;23:626–33.
[42] Nap AW, Evers JL. Couples with infertility belong to a very vulnerable group, they should not be exploited 12. Hum Reprod 2007;22:3262–3.
[43] Heng BC. Ethical issues in transnational "mail order" oocyte donation 5. Int J Gynaecol Obstetr 2006;93:302–4.
[44] Ramskold LAH, Posner MP. Commercial surrogacy: How provisions of monetary remuneration and powers of international law can prevent exploitation of gestational surrogates. J Med Ethics 2013;30:397–402.
[45] Bourg C. Ethical Dilemmas in Medically Assisted Procreation: A Psychological Perspective. Hum Reprod Genetic Ethics 2015;13:22–31.
[46] Haimes E, Taylor K, Turkmendag I. Eggs, ethics and exploitation? Investigating women's experiences of an egg sharing scheme 8, 11. Soc Health Illn 2012;34:1199–214.
[47] Hwang SW, Roh SI, Lee BC, Kang SK, Kwon DK, Kim S, et al. Patient-specific embryonic stem cells derived from human SCNT blastocysts 5729, Jun 17. Science 2005;308:1777–83.
[48] Hwand WS, Ryo YJ, Park JH, Park ES, Lee EG, Koo JM, et al. Evidence of a Pluripotent Human Embryonic Stem Cell Line Derived from a Cloned Blastocyst 5664, Mar 12. Science 2004;303:1669–74.
[49] Miller E, Silverman JG. Reproductive coercion and partner violence: implications for clinical assessment of unintended pregnancy 5, Feb 19. Expert Rev Obstet Gynecol 2012;5:511–5.
[50] WMA Statement on Assisted Reproductive Technologies. World Medical Association. Pilanesberg, South Africa : WMA; 2006.

[51] Widge A. Seeking conception: Experiences of urban Indian women with in vitro fertilisation London : Elsevier, Dec 02,. Patient Educ Couns 2005;59:226–33.
[52] Arvidsson A, Vauquline P, Johnsdotter S, Essen B. Surrogate mother - praiseworthy or stigmatized: a qualitative study on perceptions of surrogacy in Assam, India Jun 12. Global Health Action 2017;10:1.
[53] Heneghan C, Spencer EA, Bobrovitz N, Collins DR, Nunan D, Plüddemann A, et al. Lack of evidence for interventions offered in UK fertility centres 355, 11 27. BMJ 2016;17:i62.
[54] Fidler AT, Bernstein J. Infertility: from a personal to a public health problem. Public Health Rep 1999;114:494–511.
[55] Lemoine M, Ravitsky V. Toward a Public Health Approach to Infertility: The Ethical Dimensions of Infertility Prevention. Public Health Ethics 2013;6:287–301.
[56] Kamel RM. Management of the infertile couple: an evidence-based protocol. Reprod Biol Endocrinol 2010;8:21.
[57] Fertility problems: assessment and treatment. National Institute for Health and Care Excellence. London : NICE; 2017.
[58] Pennings G. Disclosure of donor conception, age of disclosure and the well-being of donor offspring. Hum Reprod 2017;32:969–73.
[59] Freeman T. Gamete donation, information sharing and the best interests of the child: an overview of the psychosocial evidence. Monash Bioeth Rev 2015;33:45–63.
[60] Frith L, Sawyer N, Kramer W. Forming a family with sperm donation: a survey of 244 non-biological parents. Reprod Biomed 2012;24:709–18 Online.
[61] Wong KA. Donor Conception and "Passing," or; Why Australian Parents of Donor-Conceived Children Want Donors Who Look Like Them. J Bioeth Inq. 2017;14:77–86.
[62] Applegarth LD, Kaufman NL, Josephs-Sohan M, Christos PJ, Rosenwaks Z. Parental disclosure to offspring created with oocyte donation: intentions versus reality. Hum Reprod 2016;31:1809–15.
[63] Lewin S, Bohren M, Rashidian A, Munthe-Kaas H, Glenton C, Colvin CJ, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 2: how to make an overall CERQual assessment of confidence and create a summary of qualitative findings table 01 25. Implement Sci 2018;13(Suppl 1):10.