D5.2.2 Report on Review of Methodologies and Ethical Frameworks in Recent Studies Related to Intersex Issues

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1. INTRODUCTION AND KEY FRAMEWORK

The definition of ethics is a process that requires the consideration of many factors since it is constantly changing under different frameworks.[i] It is possible to find meanings of "relational ethics, interactional ethics, reflexive ethics, reflexive, research ethics, contextual bioethics, critical bioethics, goodness-of-fit ethics, supported consent, individualized communication and consent, relational autonomy, everyday ethics, evidence-based research ethics, patient-oriented research, participant-centered research, person-centered research, person-oriented research and related terms",[ii] all valid to identify ethical practices. In the context of research, ethics means "the balance between our own ethics and those of the people we are studying."[iii] The need of this balance and the further evaluation of its accomplishment in research had its origin in medical research, as a result of harmful practices executed during and after the Second World War.[iv] To prevent those types of human rights violations from happening again, the international community created instruments such as the Nuremberg Code in 1947 and time after the Declaration of Helsinki in 1964 to mainly establish the importance of the well-being of research participants above any other interest.[v]

When it comes to research a particular population group that tends to be more vulnerable to acts of discrimination and abuse, the application of ethical guidelines designed since the last century to protect the participants' rights during research has been a challenging process with different concerns such as "advancing academic careers at the expense of communities, neglecting to share results, over-researching certain communities, failing to give back to communities, and stigmatizing communities by releasing results out of context."[vi] Nevertheless, the Belmont Report in 1979 was a starting point in this subject to determine the pertinence and execution of the research project and evaluating research under the principles of respect for persons, beneficence, and justice.[vii] The consequence of applying these principles is the emergence of the requirements of informed consent, risk/benefit assessment, and the selection of research subjects.[viii] From this moment, the application of these requirements in specific population groups has been a constant learning process to interpret them in a correct manner but also to respect the internal dynamics of every community.[ix]

Each population has their own history and therefore concerns that are clearly distinguishable from others. Therefore, the application of specific guidelines to research a certain population is a recommended ethical practice to obtain the best results in research, without creating scenarios that may affect the communities, such as stigmatization, or disclosure of identities.[x] For the intersex community, the research context is accompanied by a history of medicalization,[xi] imposition of gender roles,[xii] pathologizing language,[xiii] epistemic injustice,[xiv] and misrepresentation.[xv] These features have jointly created massive human rights violations and the development of harmful practices during research.

When it comes to medicalization, there are deep wounds inflicted on intersex people. Particularly since the last century the new medical understandings of intersexuality, and the clinical desire for intervention with policies such as the "optimum gender of rearing" created in the 1950s under the leadership of psychologist John Money had irreparable consequences.[xvi] This policy appeals to the earliest gender assignment (before eighteen months of age) for intersex babies to either female or male, so the child can develop 'correctly', which synonymizes what is 'good' with what can be pigeonholed in a binary gender identity and body.[xvii]

Since the practice of this policy got popular within the medical field, the birth of intersex babies meant a process of objectivization of the bodies through gender assignment, reconstruction, and "adequation" of the person into society.[xviii] The obligation to impose a gender role led to the performance of surgeries for cosmetic reasons, and the misuse of patients' personal information for medical research purposes.[xix] Thus, the environment around the medicalized model of treatment towards the intersex population was characterized by the idea of a defective body which implies a circle of pathologizing language, associating body diversity as something that needs to be fixed.[xx]

In this sense, the narrative of `repairing´ the human biology brings other two important concepts to contextualize the problematic behind the research on intersex issues: epistemic injustice, and misrepresentation.[xxi] Due to the ownership and treatment that medicine made on intersex bodies, the health professionals acquired a position of power under the name of science.[xxii] This umbrella of entitlement implies a decision-making process of what is better for intersex people without them to actively participate. Producing an atmosphere where only the medical knowledge and experiences are taken into consideration, disregarding the experiences and knowledge that the community itself can propose for its own well-being is a violation to their self-determination, and constitution of epistemic injustice.[xxiii] This epistemic injustice frames the community in a powerless stereotype where the people "variously involve an association with some attribute inversely related to competence or sincerity or both: over-emotionality, illogicality, inferior intelligence, evolutionary inferiority, incontinence, lack of 'breeding', lack of moral fibre, being on the make, etc."[xxiv]

Thus, these stereotypes can be applied to the intersex people "bringing to light the institutional mechanisms that permeate their experience, both in terms of the modes of production and circulation of knowledge guiding the actions that target them and in terms of their ability to stock."[xxv] In the process of framing these concepts within research of intersex people´s issues, it is key to comprehend better the struggles of knowledge production, and the privilege of access to knowledge that may occur in this field.[xxvi]

The objective of this report is to present an analysis of qualitative and quantitative academic studies on intersex issues and determine which methodological and ethical aspects are accomplished or missing within the reviewed papers.

2. METHODOLOGY

The narrative literature review in which this report is based on aims to identify the human rights violations in research on intersex issues across both quantitative and qualitative research. Also, it analyzes the different methodologies and ethical frameworks in research related to intersex issues. In this sense, relevant literature was analyzed to determine what are the most common ethical aspects mentioned by researchers in the development of qualitative and quantitative studies on intersex people's issues, and what could be possible ethical conflicts or human rights violations that occur within research. The selection process of the academic articles was determined by the methodology used: either qualitative or quantitative research on intersex people´s issues. Papers were selected that have been published after August 2006, year when the Chicago Consensus[xxvii] was released until August 2022.

In total 24 papers were analyzed: twelve papers based on qualitative studies and twelve on quantitative studies.[xxviii] Within the analysis, two main categories were established: methodological aspects and ethical aspects. The methodological aspects were divided in three subcategories: sample and access, research techniques, and methods of analysis. The ethical aspects were divided in four subcategories: research ethics boards, informed consent, data management, and ethical frameworks and practices. The purpose of these categories was to determine if the academic papers studied had in consideration these fundamental aspects during the research development.

3. REVIEW OF SELECTED QUALITATIVE / QUANTITATIVE STUDIES

The following chart enlist the 24 papers studied to get a better overview:

TITLE	YEAR	RESEARCH DESIGN	AUTHORS	DOI
Intersex individuals’ religiosity and their journey to wellbeing	2009	Qualitative	Kerry.	doi.org/10.1080/09589230903057092
Screening of Genital Anomalies in Newborns and Infants in Two Egyptian Governorates	2010	Quantitative	Mazen et al.	doi:10.1159/000313588
Sexual function and surgical outcome in women with congenital adrenal hyperplasia due to CYP21A2 deficiency: clinical perspective and the patients’ perception	2010	Quantitative	Nordenström et al.	doi:10.1210/jc.2009-2639
Satisfaction with Genital Surgery and Sexual Life of Adults with XY Disorders of Sex Development: Results from the German Clinical Evaluation Study	2012	Quantitative	Köhler et al.	doi:10.1210/jc.2011-1441
DSD and Professionalism from a Multilateral View: Supplementing the Consensus Statement on the Basis of a Qualitative Survey	2012	Qualitative	Streuli et al.	doi:10.1155/2012/185787
Syndrome-Related Stigma in the General Social Environment as Reported by Women with Classical Congenital Adrenal Hyperplasia	2016	Qualitative	Meyer-Bahlburg et al.	doi:10.1007/s10508-016-0862-8
Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: afeasibility study	2017	Quantitative	Bougnères, Bouvattier, and Cartigny.	doi.org/10.1186/s13633-016-0040-8
Evaluation and treatment for ovotesticular disorder of sex development (OT-DSD) - experience based on a Chinese series	2017	Quantitative	Mao et al.	doi.org/10.1186/s12894-017-0212-8
Analysis of Presentations and Outcomes of Care of Children with Disorders of Sexual Development in a Nigerian Hospital	2018	Quantitative	Mieszczak, Houk, and Lee.	doi.org/10.1016/j.jpag.2018.08.005
Disorders of sex development: timing of diagnosis and management in a single large tertiary center	2018	Quantitative	Kohva et al.	doi:10.1530/EC-18-0070
Shaping parents, shaping penises: How medical teams frame parents’ decisions in response to hypospadias	2018	Qualitative	Roen, and Hegarty.	doi.org/10.1111/bjhp.12333

Legislating intersex equality: building the resilience of intersex people through law	2018	Qualitative	Garland, and Travis.	doi.org/10.1017/lst.2018.17
Does Patient-centered Care Change Genital Surgery Decisions? The Strategic Use of Clinical Uncertainty in Disorders of Sex Development Clinics	2018	Qualitative	Timmermans et al.	doi:10.1177/0022146518802460
Briefing Paper: What do intersex people want from the law?	2018	Qualitative	Garland, and Travis.	
Special Parents for “Special” Children? The Narratives of Health Care Providers and Parents of Intersex Children	2019	Qualitative	De Clercq, and Streuli.	doi: 10.1353/nib.2019.0026
The Modified McIndoe Technique: A Scar-free Surgical Approach for Vaginoplasty With an Autologous Micromucosa Graft	2019	Quantitative	Teng et al.	doi:10.1016/j.urology.2019.05.020
Drawing the Line Between Essential and Nonessential Interventions on Intersex Characteristics With European Health Care Professionals	2020	Qualitative	Hegarty et al.	doi.org/10.1177/1089268020963622.
Inside the doctor’s office. Talking about intersex with Italian health professionals	2020	Qualitative	Prandelli, and Testoni.	doi:10.1080/13691058.2020.1805641
‘You’re basically calling doctors torturers’: stakeholder framing issues around naming intersex rights claims as human rights abuses	2020	Qualitative	Crocetti et al.	doi.org/10.1111/1467-9566.13072
Intersex lived experience: trauma and posttraumatic growth in narratives	2021	Qualitative	Hart, and Shakespeare-Finch.	doi.org/10.1080/19419899.2021.1938189
Recommendations of patients and families of girls with 46XX congenital adrenal hyperplasia in the United Kingdom regarding the timing of surgery	2021	Quantitative	Shalaby et al.	doi: 10.1007/s00383-020-04780-3
Staged transverse preputial island flap urethroplasty for some proximal hypospadias with moderate-to-severe chordee	2021	Quantitative	Lin et al.	doi:10.1186/s12894-021-00948-8
Quantitative proteomics reveals specific protein regulation of severe hypospadias	2022	Quantitative	Zhu et al.	doi:10.21037/tau-22-155
One-stage tubularized urethroplasty using the free inner plate of the foreskin in the treatment of proximal hypospadias	2022	Quantitative	Shi et al.	doi:10.1186/s12887-022-03464-2

3.1. Methodological Aspects

3.1.1 Sample and access

Most of the reviewed papers indicate a defined target group within the intersex community. In the quantitative papers, the selection criteria are very specific, and mostly refer to health conditions that the intersex person may have, or medical procedures that an intersex person went through, also some papers consider the range of age to classify as a participant in the quantitative research. In the case of the qualitative papers, some of the criteria are the activist profile of the people, belonging to a particular group or living in a specific country.

Regarding the access of the sample, within the twelve reviewed quantitative studies, four papers did not clarify how the researchers approached the participants. In the other eight, the access was given through support groups of particular health conditions, or through the hospital databases where participants had some medical procedure. This last form of access is also used in the reviewed qualitative studies. Besides, in the qualitative papers, the vast majority explain the access to the sample through other methods such a snowball recruitment, or directly contacting the participants via e-mail.

3.1.2 Research techniques

The strategies to collect the data constantly vary in each research, particularly in the quantitative papers. Here, there are papers where data was collected by reviewing the medical records of the participants, through surveys, or through the observation of the participants after a medical procedure. In the analyzed qualitative papers, the research techniques are more homogeneous. The majority of authors conducted interviews with different type of questions like semi-structured or open-ended questions, some of them used audio recordings, or implemented follow-up interviews.

3.1.3 Methods of analysis

The methods of analysis of the information gathered are diverse in both types of research. In the quantitative studies, the majority of the authors implemented different scores and values, some used statistical methods such as the Kruskal–Wallis test, Whitney U test, or Chi-square test. In the reviewed qualitative studies, many of the authors used thematic analysis, interpretative phenomenological analysis, or deductive content analysis. A small minority of both types of studies does not mention their method of analysis.

3.2. Ethical Aspects

3.2.1 Research ethics boards

Within the 24 consulted papers, the approval of the project by a research ethics board is included in the text of 14 papers. Five of them quantitative studies and nine qualitative studies. The remaining 10 papers do not specify whether or not there was a previous approval of a research ethics board.

3.2.2 Informed consent

From the 24 reviewed papers, 15 papers do mention the participants' informed consent, 9 quantitative studies and 6 qualitative studies. Out of these 15 papers, 5 did not mention anything related to ethical approval, 4 in quantitative studies and 1 in qualitative studies.

3.2.3 Data management

In the case of the reviewed quantitative studies, some of the authors clarify that the data described in the papers are available to use with prior consent of the authors, making statements like: "all data and materials can be obtained by mail of the corresponding author."[xxix] For the qualitative studies, the vast majority of the authors audiotaped and transcribed the gathered information, some of them use particular software or certified companies to manage the data.

3.2.4 Ethical frameworks and practices

Within the analyzed 24 papers, the most common ethical framework is the declaration of no conflict of interests by the authors. In the case of quantitative studies, two of twelve papers mention ethical practices like: "the assessment of the individuals with DSD was conducted by trained psychologists during personal encounters,"[xxx] or "ethical statement: the authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved."[xxxi]

In the case of qualitative studies, four papers mention ethical frameworks. Some state the use of ethical guidelines: "given the sensitive nature of this topic, the authors ensured that the study complied with the SLSA's ethical guidelines."[xxxii] Other ones highlight the preparation needed for the research to conduct the interviews: "due to the sensitive research topic, interviewers were trained to use a dialogical approach, since this allows the researcher and interviewees to explore multiple meanings, narratives, implicit frames of reference and practices."[xxxiii] Furthermore, some ethical practices can be observed to protect the identity of the participants (for example "for ethical reasons, the interviewer emphasized the importance of not disclosing identifying details about patients, and any potentially identifying details were removed from transcripts prior to analysis")[xxxiv] and to make sure the questions were appropriate (for example "the authors also asked individuals from two independent intersex organisations (one UK-based, the other USA-based) to scrutinize the interview schedule and information sheets.")[xxxv]

4. DISCUSSION AND CONCLUSIONS

Research grounded in a human rights-based approach and ethical frameworks is critical for ensuring that a community that has suffered violations of their human rights does not go through possible scenarios that create them any harm within the research process.
The literature review made it possible to distinguish different features in the reviewed qualitative and quantitative papers. While in the quantitative studies, the sample is more specific in most of the studies, the access was in the majority given to the researcher through a certain link that the participant had with a medical institution, such as: “from September 2011 to December 2015, 16 patients with OT-DSD were evaluated and treated in our hospital."[xxxvi] This shows that in some academic papers, the researcher is at the same time the doctor that performs a medical intervention to the patient/participant.

For the case of the reviewed qualitative studies, the sample is broader in most of the studies, but the access seems to require a more direct connection to the participant, for instance: “suitable participants were identified and contacted through organizational websites and also by snowballing. The sample includes individuals from non-responsive states like the UK, Denmark, USA and Sweden; status-based states like Australia and Germany; and holistic states such as Malta and Iceland."[xxxvii] Thus, through the analysis of these two dynamics it is possible to observe previous relationships between researchers and participants in some of the papers, raising the question how this may influence the research process.[xxxviii]

Besides the review of the research methodology, one of the purposes of the literature review was to analyze the ethical frameworks present in both types of research. In 22 of the 24 papers, the main aspects such as the informed consent and data management were exposed in general terms, or not clearly exposed at all in some of them. Also, there are particularities in a few manuscripts that raised attention, for example in some of the quantitative studies, there was a presence of pathologizing language with the use of words such as “the other patient had a normal looking vagina”[xxxix] or “as the appearance of bisexual phenotype and continuous anxiety of parents call for the management, it is rational and, in a degree, mandatory to initiate the evaluation at an early age.”[xl] The presence of images is also very controversial because although it is not possible to recognize the participant, it may bring a sensation of discomfort and pain to watch these pictures, and raise the question: How does the participant feel regarding the public character of these images and their right to privacy? Was clear in the informed consent form the kind of pictures that would be published?

Significant reflections on pathologizing language and image use within intersex studies have been made to point out the importance of “using and promoting respectful, affirmative and non-pathologizing conceptualizations and terminologies”[xli] and “[a]bstaining from a use of pathologizing images in publications or presentations.”[xlii] The idea of these practices is to promote an ”ethics of depathologization”, understanding it as “a research practice based on the depathologization and human rights perspective, developed in the field of trans and intersex studies, but applicable to different research topics, knowledge fields and situations of structural violence and epistemic injustice.”[xliii]

Continuing with the reviewing of ethical frameworks, it was interesting to observe that out of 24 papers, only one (a qualitative study) mentions a specific training that was provided to the researchers to be able to perform better research practice. The document states: “the interviews were conducted by three Caucasian students (1 woman and 2 men) for a final year project in social psychology, after receiving specific training on the research topic and methodology.”[xliv] Acknowledging the internal dynamics of a vulnerable population and understanding their history, struggles and claims is a crucial aspect within research ethics,[xlv] in both qualitative and quantitative research, the responsibility of knowledge production towards the community and the results of the research should go in the same line. Otherwise, there could be a risk of problematic practices and therefore re-traumatization of the participants in the research context.[xlvi]

As it was mentioned in the introduction, the idea of ethics can include many different meanings. Although the viewpoints can be diverse, there must be certain unbreakable standards to protect the participants' rights. Still, there is a long way to go to the application of ethical frameworks. Although within this literature review it was possible to determine some common ethical grounds in both types of research, such as the informed consent, it is important to go further when it comes to safeguard the participants´ identity, beliefs or needs. Being aware of the big responsibility of the researchers in the production of ethical knowledge is an ongoing task, particularly when the research involves a community that have possibly been exposed to human rights violations.

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