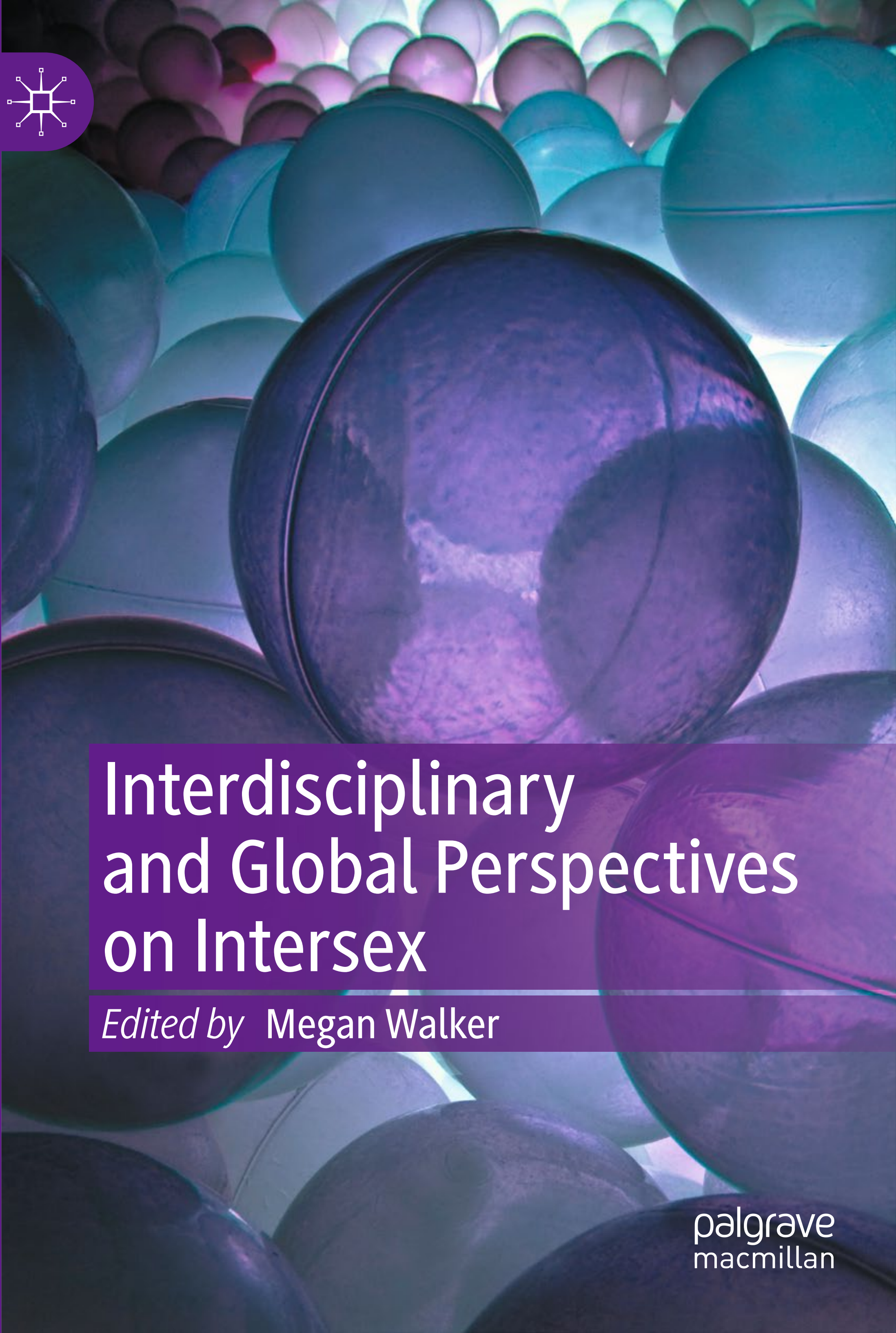

Interdisciplinary and Global Perspectives on Intersex

Edited by Megan Walker

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This collection of chapters is primarily made up of conference papers that were delivered at the 'Interdisciplinary Perspectives on Intersex' conference (IPI2019) at the University of Lincoln in 2019. This conference was hosted by the Eleanor Glanville Centre, which is an equality, inclusion and diversity centre at the University of Lincoln. Special thanks must go to the Eleanor Glanville Centre and its members, including Prof. Lucie Armitt, Prof. Belinda Colston and Mrs. Leila Lamoureux for making up the planning and working committee of the conference. You all went above and beyond to make the conference a reality and I am extremely grateful for your support, encouragement and guidance. I would also like to express my gratitude to Valentino Vecchietti who spent many hours contributing to the planning of the conference.

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A special thanks must also go to my husband Dr Callum Walker for helping with the practicalities of putting this collection together. Your reassurance and assistance in ICT problem solving, proofreading, sharing childcare duties and keeping me in a constant supply of coffee will never be forgotten.

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Michela Balocchi is a postdoctoral researcher and activist for intersex human rights. She holds a PhD in Sociology and Political Sociology. Balocchi is a Prior Marie Curie Fellow, with an individual project on the 'Sociological Aspects of the Management of Intersex Variations'. She has collaborated with many universities as lecturer, adjunct professor and researcher. She has been on the scientific board of the Center of Research PoliTeSse at the University of Verona since its founding. She co-founded the group 'intersexioni' and she is the web editor of the namesake website. Her research interests include gender studies, social inequalities and intersex studies.

Morgan Carpenter is a bioethicist, executive director of Intersex Human Rights Australia and creator of the intersex flag. He plays an active role in systemic advocacy on legislative, regulatory and clinical reform. A signatory of the Yogyakarta Principles plus 10 and a participant in the first UN expert meeting on ending human rights violations against intersex persons in 2015, he has acted as a consultant to the UN Office of the High Commissioner for Human Rights, World Health Organization, Australian Capital Territory government and an advisory group member for the Australian Human Rights Commission and New South Wales Health.

Arpita Das is a PhD candidate in the Department of Gender and Cultural Studies at the University of Sydney, Australia. She also holds Master's degrees in Social Work and Women's and Gender Studies. Her doctoral research is focused on examining medicalisation of intersex bodies in India. Her academic interests are intersex issues, gender and sexuality, and reproductive technologies.

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Peter Hegarty is a social psychologist and Historian of Psychology. He has researched how people make sense of diverse sex development and the medical interventions that can be brought to bear on it and public understanding of such development and its medicalisation. He is a member of the American Psychological Association's Task Force on differences of sex development.

Charlotte Jones is a postdoctoral research fellow at the Wellcome Centre for Cultures and Environments of Health, University of Exeter, UK. Her research addresses issues of gender, sexuality, disability and health, and particularly the intersections of these areas. In 2016 she was awarded her PhD on the medicalisation of sex in the UK, and the impact of VSC/I diagnoses on relationships, identity and recognition. Since then, she has led collaborative research focusing on VSC/I (variations on sex characters/intersex), in/fertility support and relationships.

Christopher F. C. Jordens is an honorary associate professor in the Faculty of Medicine and Health at the University of Sydney, where he has worked for 25 years. He has been a chief investigator on numerous studies focusing on social and ethical aspects of medicine and health. He was a founding co-editor-in-chief of the *Journal of Bioethical Inquiry*, and he played a leading role in establishing the postgraduate bioethics programme at the University of Sydney in which he taught from 2006 to 2021.

Ino Kehrer is a PhD student of the international joint PhD programme 'Human Rights, Society and Multi-Level Governance' coordinated by the Human Rights Centre of the University of Padova, Italy, and part of the group 'intersexioni'. She Graduated in Law from the Alma Mater Studiorum, University of Bologna. In her research through a comparative study, she examines the challenges to the protection of sex and gender diversity stemming from dichotomous legal categories under international human rights law. Her most recent co-authored publication is *The Bio-medicalization of Intersex Variations Between Medical and Parental Authority* (Palgrave Macmillan, 2020).

Lih-Mei Liao is a retired consultant clinical psychologist and head of the department at a leading NHS hospital. During her working career, Liao remained research-active, particularly in the field of intersex, but also in women's health more broadly. With equally passionate colleagues, she co-founded academic and professional networks, co-authored national and international care guidances, served on strategic committees and editorial boards and consulted to groups and institutions in the UK, Continental Europe and the USA. In 2020, she retired from the NHS to spend time with family and friends; to have more time to consult to diverse individuals and groups in the public, private and third sectors; and to write.

Limor Meoded Danon is a sociologist specialising in the fields of medicine, body, sex/gender relations and bio-politics. She is affiliated with the medical faculty at Bar-Ilan University, Israel. Her studies focus on the dynamics between the biomedical knowledge and the patients' physical and emotional experiences, as well as socio-cultural perspectives on normative/pathological bodies.

Chris North is a 74-year-old intersex person and has joined the intersex community 4 years ago. He has extensively researched his life and written a graphic novel alongside his autobiography. North has been a teacher, social worker and creative arts facilitator. He aims to contribute to intersex understanding and the movement for change. He does voluntary work as an outreach speaker, including for IntersexUK. He is an advocate and intersex ally.

Chiara Pellegrini is a PhD candidate in English Literature at Newcastle University, UK. Her project focuses on contemporary novels and autobiographies with gender-variant first-person narrators. Her background is in queer theory, trans studies, narrative studies and continental philosophy. She has recently written two articles: 'Posttranssexual Temporalities: Negotiating Canonical Memoir Narratives in Kate Bornstein's *Gender Outlaw* and Juliet Jacques' *Trans*' (*a/b: Auto/Biography Studies*, 2019) and 'Adaptation as Queer Touching: Transgressing the Boundaries of Bodies and Texts in *The Safety of Objects*' (*Queer/Adaptation*, ed. by Pamela Demory, Palgrave Macmillan 2019). Her interview with author Juliet Jacques has been published in *Transgender Studies Quarterly* (2020).

Kamran Qureshi is an award-winning British Film and Television Director. His PhD was in Professional Practice Film, TV and Media at the University of East Anglia. His research work on intersex includes US television drama series, English language feature films, Indian Cinema, Australian Film and TV, along with directorial experience of telemovie *Murad* (2003), and 32-part TV series *Moorat* (2005) and his new feature film *Only Love Matters* (2022), the first movie in cinema history on intersex subject set in Britain.

Megan Walker is an associate lecturer in the College of Arts, University of Lincoln, UK. Walker's research project is a medical humanities thesis on the subject of narrative representations of intersex individuals. Walker explores intersex narratives in a range of texts including medical texts, patient case histories, fiction, life-writing, televisual series and the media with the aim of establishing how intersex representations and cultural in/visibility have changed in the twentieth and twenty-first centuries. Walker has a keen interest in public engagement, interdisciplinary research and collaboration to further develop intersex knowledge, visibility and acceptance in academia and beyond.

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CHAPTER 1

Introduction

Megan Walker

Intersex is defined by the United Nations as referring to people ‘born with sex characteristics that don’t fit typical definitions of male and female’ (United Nations Free & Equal, n.d.). Variations of sex characteristics may include chromosomal, gonadal, physiological or hormonal traits that vary from typically believed male or female presentation. Since the 1950s, intersex children have been subjected to non-consensual, irreversible, cosmetic genital surgery to make their genitals appear more typical (Karkazis, 2008). Many of these medical interventions are known to cause long-lasting, traumatic after-effects (Karkazis, 2008). The prevalence of intersex variations is a contested issue, but recent sources suggest that up to 1.7% of the population is born with a variation of sex characteristics, which makes having an intersex variation as common as having naturally occurring red hair (UN Free & Equal, n.d.).

Since the early 1990s, there has been an increasing amount of interest around the subject of intersex variations and, in particular, a scrutiny of the longstanding human rights issues surrounding the medical treatment that these individuals receive, often during childhood. This interest has

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largely stemmed from the formation of early intersex rights organisations such as the Intersex Society of North America (ISNA) in 1993. It was with the support of these organisations that people with intersex variations spoke out for the first time about the traumatic experiences they had whilst undergoing medical interventions for their intersex variation and campaigned for unnecessary, non-consensual surgery on children with intersex variations to stop (ISNA, 2008). We are now an in epoch when minority groups have greater representation than ever before in history. For example, LGBT+ rights have made huge strides in the last few decades with many institutions now recognising sexualities and gender identities other than "heterosexual" and "cisgendered". That is not to say that equality has been reached; we still have a long way to go. However, positive change is occurring for those who do not conform to heteronormative sexual and gendered identities.

Conversely, despite the positive steps that have been taken in recent years, intersex rights lag behind those of other minority groups. Despite increased activism and academic, legal and medical interest in intersex variations for almost 30 years, there is still very little wider acceptance of those with intersex variations. This lack of acceptance is reflected in the larger medical community through the continued practice of performing medical interventions on children with an intersex variation to "normalise" their bodies. Despite renewed guidelines being released in 1997 (Diamond & Sigmundson, 1997) and 2006 (Peter Lee et al., 2006) stating that surgical and hormonal intervention should be avoided until a patient is of an age when they can make an informed choice, recent studies show that the number of medical interventions on children with an intersex variation has not decreased (Crocetti, 2019). This lack of progression in the area of intersex rights leads us to question why further progress has not been made. Perhaps the answer lies in representation. Throughout history, great social and legal change comes from the call of the masses. Consider the campaign for the abolition of slavery which led to the Slavery Abolition Act 1833 (The British Library, n.d.-b), the suffrage movement resulting in The Representation of the People Action 1918 (The British Library, n.d.-a) or the so-called Attenborough effect on the reduction of plastic use following the airing of *Blue Planet II* (Shukman, 2019). Currently, society is so ingrained in the notion that our world is organised by a two-sex binary division that it seems more problematic for a child to sit outside that binary division than it does for medical professional to "treat" or "fix" the child. As long as the narrative of treatment, disorder and deformity prevails, intersex variations will continue to be seen as a treatable medical condition rather than the naturally occurring variations that they are.

Objectives

This book brings together a collection of essays from a broad range of academic specialisms. The majority of the contributions started life as conference papers delivered at the Interdisciplinary Perspectives on Intersex (IPI2019) which was hosted by the Eleanor Glanville Centre at the University of Lincoln in July 2019. The conference was born out of the desire to bring all the strands of the contemporary intersex movement together to further intersex knowledge. The contributions included in the collection come from the fields of psychology, bioethics, sociology, law, literature and film studies. By placing these essays together in one collection, the aim is to continue the legacy of IPI2019 and draw together the threads of the wider, but interconnected work currently taking place in intersex studies.

By integrating new research from the humanities and the social sciences, this volume offers a unique contribution to the field by interrogating the representation of intersex variations culturally, socially, legally and medically from around the world. Together, the interdisciplinary contributions to this collection show that the ways in which intersex variations are represented through language and cultural perceptions directly impact on the response to individuals with intersex variations globally. Once the reliance upon regulatory control systems such as sex differentiation, cultural discourse, gender bias, medicalisation and pathologisation have been broken down through an examination of how these barriers are constructed, it is possible to recognise intersex variations as a natural difference that is not in need of “treatment”. Many of the contributions in this book from a diverse array of fields mobilise renewed recommendations or explore alternative practices by presenting important and impactful research findings.

This diverse collection showcases the great potential and challenges of this still relatively new, but rapidly growing field. The diversity and innovation inherent in this area is clear to see from the broad range of subjects broached by the contributors. The themes running through the collection are those of intersex representation, medical responses to intersex variations and intersex human rights, with much of the current research focusing on these areas. This collection will be the first of its kind to highlight the importance of research into intersex in the arts and is actively combating epistemic injustice by proudly positioning the arts alongside more widely established disciplines in intersex. All these essays share equally important and crucial research in intersex studies. By focusing on the topic of representation, the collection emphasises the role the arts and humanities can play in furthering intersex studies as a discipline. Therefore, in recognising the importance of language and representation, intersex studies as a dialogic and interdisciplinary research area can move forward with the strength of multiple schools of thought working together to further intersex knowledge.

"Part I, Representing Intersex", considers some of the different ways in which novelists, filmmakers, artists, medical professionals and other stakeholders have represented people with intersex variations. Representing Intersex explores the importance of representation through different media: film, twenty-first century fiction, medical reports, poetic and environmental texts, self-reported experiences in diary entries and bioethics and advocacy. These contributions address agency and authorship through an analysis of different forms of representation. Part I highlights the importance of ethical representation and autonomy in intersex representation to encourage a wider cultural and medical knowledge of intersex variations as a naturally occurring phenomenon. By separating narrative representation of gendered norms and sexual differentiation from the latest evidence reflecting intersex voices, these chapters offer exciting and unique ways of representing intersex variations with the aim of improving intersex care in the future.

"Part II, Global Intersex", examines how intersex variations are represented and responded to in different cultures globally. The contributions in Part II also have a strong focus on how social, cultural, legal and medical representation has an impact on the reaction to intersex traits and medical, familial and individual decision-making. Many of these chapters focus on analysing the discourses that govern the representation of intersex traits in order to examine the response to intersex variations and the decision-making process in India, Italy, Pakistan, Israel and Western nations. Part II emphasises the importance of cultural narrative representation and the positioning of social, cultural and medical situations around the world and examines how these representations can be read and interpreted through an analysis of the dominant cultural discourse in relation to other related subjects like transgender rights, consent and autonomy.

The book concludes each section with an Afterword. The two Afterwords offer a critical analysis of the chapters in each representative section as well as emphasising the importance of representing intersex variations and global, interdisciplinary research. The authors offer suggestions for further reading, provide information on any upcoming or much needed research and activist work while sharing how their own experience, research and activism feeds into the thematic issues in each section.

Through an exploration of medical and social discourse, narrative analysis, social positioning, cultural discourse and social norms across many disciplines and different countries, this book argues that reactions to intersex variations will not change until they are no longer presented linguistically, culturally and socially as treatable disorders that situate intersex individuals outside the social binary division of male/female and gendered norms. The book positions representation at the forefront of intersex studies, shifting the emphasis away from a concern for maintaining gender norms to upholding the human rights of people with intersex traits.

The Field of Intersex Studies

First, we should address the growth of intersex studies across multiple disciplines in recent history, providing a brief overview of the field of intersex studies from its inception to more recent publications. With the beginning of DSD nomenclature that has been taken up by some scholars since 2005 onwards, some may argue that the field of intersex studies is drawing to a close and progressing into DSD (disorders/differences of sex development) or VSC (variations of sex characteristics) studies. However, to quote Morgan Holmes in her edited collection *Critical Intersex* (2009), 'we (whether we are scholars, intersexed persons, activists or some combination of these three) are not yet done with "intersex"' (Holmes, 2009, p. 1). This statement does not reflect a desire to ignore the current contentions around terminology; we are in an era of conflicting terminological uses and this collection has tried to acknowledge this difficulty and account for it by allowing each author to make their own decisions on terminological uses. The mixture of nomenclature throughout the collection is intended to reflect the current conflicts within the discipline over terminology and the highlight the work that still needs to be done in this area. It is outside the bounds of this book to comment on possible future work regarding nomenclature, but the collection as a whole aims to be inclusive of all the currently recognised and accepted terminological choices. However, born out of a desire to avoid pathological language, the title of the book evidently displays a preference for the language of "intersex" over terms that imply that intersex variations are a kind of "disorder" that require medical "treatment". Instead, the book aims to promote positive representation and acceptance of intersex variations or variations of sex characteristics. Despite this preference, what is crucial is that the negotiations about terminology do not derail important, collaborative and impactful research from taking place. Thus, the individualised and inclusive nature of all uses of terminology in the book aims to avoid any such dismissal of any one area of research.

While there is a long and varied history of intersex research in more medical-based disciplines dating back to the early 1900s and even before, this overview will focus on what might be considered to be the starting point of intersex studies. This collection pinpoints this starting point, in academia, to the publication of Suzanne Kessler's 1990 journal article in *Signs*, entitled 'The Medical Construction of Gender: Case Management of Intersexed Infants'. In this ground-breaking article, Kessler exposes the medical management of infants with an intersex variation and the use of normative gender stereotypes to inform their treatment recommendations. Kessler's ensuing book, *Lessons from the Intersexed* (1998) was one of the first publications to broach the subject of intersex human rights and the injustices that occur within the medical management of intersex variations in the name of maintaining the two-sex binary division. From the information she collected in interviews with parents of intersex children and intersex adults, Kessler proposed new approaches for physicians to use when addressing intersex children and their parents. In 2003, sociologist Sharon Preves published *Intersex and Identity: The Contested Self* in which she reports on interviews with adults with intersex variations who underwent medical interventions as children. In this book, Preves explores the identity formation of intersex individuals despite medical attempts to encourage the formation of a singular gender identity in intersex patients. Preves asserts that medical interventions are often responsible for the stigma that individuals with intersex variations face, a view that continues to be held today.

Katrina Karkazis, an anthropologist and bioethicist, published *Fixing Self: Intersex, Medical Authority, and Lived Experience* in 2008. Karkazis' book focuses on the medical management of intersex variations in the United States by drawing on interviews from people affected by these interventions as well as medical professionals. She poses important questions about the need for medical intervention and the dangers of viewing intersex variations through the medical lens alone. Morgan Holmes, a sociologist and intersex activist, published *Intersex: Perilous Difference* in 2008, which is the first monograph about intersex representation and provides analysis of twentieth-century representations of intersex in popular media such as novels and television series as well as readings of medical files. Holmes highlights how these popular representations relegate intersex characters into deviant roles while also emphasising how people with an intersex variation are forced into normative categories in order to align with the two-sexed binary division. In 2009, historian Elizabeth Reis provided an important and informative history of intersex and reactions to intersexuality in the United States and provided the contextual information for many current researchers in this area. Also in 2009, Morgan Holmes produced an edited collection entitled *Critical Intersex*. Holmes' book was the first of its kind and brought together interdisciplinary experts in the field to challenge the scope of intersex studies. Moving forward six years, in 2015, Georgiann Davis published her monograph *Contesting Intersex: The Dubious Diagnosis*. Davis' monograph draws on interviews with patients, the parents of patients with an intersex variation and medical practitioners to uncover the ways in which the medical community frames intersex visibility. Davis' book provides an important contribution to intersex studies through its updated findings, from interviews, regarding medical practice and the ways in which intersex is represented in the medical community.

This brief summary cannot possibly reflect the full extent of the work published in intersex studies, but provides a rudimentary overview of key books that have been published to date. This book offers just a snapshot of the wide range of work that is happening in intersex studies right now and aims to highlight the growth and reach of this field of research through a truly interdisciplinary community of researchers.

Contributions

"Part I: Representing Intersex" opens with a chapter by Eva De Clercq, which focuses on how the inclusion of characters with intersex variations in film plays an important role in educating the general public about intersex variations because of the broad range and appeal of film. She offers a systematic review and critical analysis of the narrative portrayal of intersex representation in the history of cinema. De Clercq also considers the pitfalls of film representation including the old narrative rhetoric of individuals with intersex variations as freaks, criminals or femme fatales and highlights how the intersex body may be interpreted with a kind of morbid curiosity, rather than in a liberating and educational way.

Chiara Pellegrini's chapter considers the ethical relationship between authors, narrators and audience through literary representations of intersex people at the beginning of the millennium. By examining the narrative choices in Jeffrey Eugenides' *Middlesex* (2002) and Jordy Rosenberg's *Confessions of the Fox* (2018), she argues that texts can either replicate or challenge dynamics of exposure, surveillance, erasure and silencing through narrative acts of looking, hiding, speaking and revealing. By negotiating texting visibility, Pellegrini explores the authors' choices to either expose or refuse to expose the bodies of their protagonists.

Megan Walker's contribution also draws heavily on narratological studies, considering the importance of narrative and significance of language in intersex representation. Her chapter begins with an exploration of how intersex variations have been represented, with reference to the mythical origins of Hermaphroditus. She then performs a literary reading of John Money's multiple works dating from the 1950s onwards, positioning them as stories in which he construes patients as characters in his subjective narrative. Walker's chapter concludes by underlining the importance of language and the different ways in which narrative is employed to represent intersex variations.

K.J. Dykstra's chapter offers a further literary contribution and considers how intersex bodies are represented as an occurrence caused by our planet becoming more toxic as a result of human consumption. Dykstra explores the notion that we are in an age of 'transsex panic' in which media outlets, scientists and environmentalists have positioned intersex bodies as the result of the negative effects of human-made chemicals on Earth. They perform an imaginative reading of Aaron Apps' poetry collection *Intersex: A Memoir* through a Deleuzean lens to explore how our current medicalising age offers limited liveability for intersex lives.

Charlotte Jones' contribution addresses the complexity of agency, authorship and content control in intersex research by reflecting critically on what it means to conduct research *on* or *with* intersex people and identifies some of the ethical and methodological considerations of working with participants in this field. Drawing on her own qualitative projects using solicited diaries and people with intersex traits and parents of intersex children in the UK, she considers different approaches to designing intersex-focused research. Jones discusses autonomy, independence and choice of format as some of the benefits that the diary-interview method offers while sharing her own reflections of the method.

Morgan Carpenter and Christopher F. C. Jordens consider the relationship between bioethics and advocacy. Drawing on prominent discourses of medical and social intersex positioning and the representation of intersex as a medical issue (rather than a social issue), the authors highlight the importance of advocacy when bioethics fails, such as in the case of how the medical community responds to intersex variations with outdated and non-evidence-based medical interventions. Carpenter and Jordens discuss a number of important, but potentially uncomfortable topics including secrecy, informed consent, infanticide and foetal elimination and medical complicity in withholding information to influence parental decision-making.

Part I closes with Peter Hegarty and Chris North's Afterword on Representing Intersex. Hegarty and North offer an innovative, multi-faceted dialogue based on their varied perspectives and diverse backgrounds. In addition to engaging with the chapters in this section, the authors ask larger questions and explore work that still needs to be carried out in intersex studies. Opening with an extract of Natalie's diary entry in Jones' chapter, and following an analysis of Natalie's creative process, the authors note the importance of listening and pose a series of insightful questions about how we listen to diverse accounts of intersex experience in different modes. Hegarty and North close with a call for the inclusion of the representation of intersex in music, an analysis of how intersex and endosex people make sense of texts written by and about intersex people and more research into the religious experience for individuals with intersex variations beyond Western religious traditions.

"Part II: Global Intersex" opens with Arpita Das' contribution that examines issues of autonomy and consent for people with intersex variations in India. In her chapter, Das explores social, cultural and medical discourses that govern how medical professionals make decisions about sex and gender assignment of children with intersex variations in India. Through an analysis of her qualitative interviews with doctors across India, she explores different layers of consent and participation with regards to bodily autonomy for people with an intersex variation.

Michela Balocchi problematises the theoretical and practical management of intersex variations by the medical community in Italy. Drawing upon her qualitative research, she stresses the human rights implications resulting from the current erasure of intersex subjectivity caused by the medicalisation of intersex variations through the wide range of non-essential, cosmetic, and irreversible surgeries that are carried out on children with intersex variations in Italy. Balocchi highlights the social discourses that drive the medicalisation of people with intersex variations while also highlighting the lack of appropriate and specialised health care available to patients.

Kamran Qureshi's chapter offers a comparative study of the Transgender Persons Act, 2018 in Pakistan and the United Nations Office of High Commissioner of Human Rights recommendations in 2016. In order explore the outcomes of Transgender Persons Act, 2018 in Pakistan, Qureshi uses content analysis to compare 50 news reports from Pakistani and international media outlets and examine how people with intersex variations are represented in Pakistan. He highlights important cultural differences of intersex representation in Pakistan, including intersex being referred to under the umbrella term transgender and the welcome introduction of a third gender category.

Ino Kehrer's chapter explores the concept of harmful traditional and cultural practices and the way these practices are now recognised as issues through the work of specialised United Nations agencies and human rights bodies. She highlights the inherent Western and gender bias in the current notions of harmful practice. By comparing medical interventions on children with an intersex variation to female genital mutilation, Kehrer analyses whether elective surgeries on children with intersex variations should be construed as harmful practices. Through a thorough examination of the criteria that must be met to deem a medical practice harmful, Kehrer argues that there are sufficient grounds for elective medical interventions to "normalise" the appearance of the genitals of a child with an intersex variation to be considered harmful practices due to the decisions to perform these interventions on the child being based on social and cultural norms.

Limor Meoded Danon explores the geneticisation process of intersex variations in Israel. Through a literature review of the latest genetic discoveries of intersex/DSD variations and interviews with 15 Israeli geneticists and gynaecologists, this chapter examines how the geneticisation process, which is a global phenomenon, is manifested in the local Israeli use of assisted reproductive technologies for prenatal testing for intersex variations. Meoded Danon discusses important, but controversial topics including the increasing use of genetic testing during pregnancy, genetic determinism, eugenic practices and terminations of pregnancy due to genetic differences.

Lih-Mei Liao's chapter exposes the gap in patient-centred intersex/DSD care that is currently unacknowledged in Western medical communities. She stresses the need to recognise this issue in order to realise an integrated approach in multi-disciplinary teams going forward. Liao highlights, from a wealth of recent studies, that psychosocial experts are positioned as silent and passive partners and are often excluded from communicating with families during the early stages of medical intervention despite being best placed to frame the information in an appropriate manner to families. Instead, medical interventions and medical staff are prioritised, with psychological support often coming too late. Liao concludes her chapter by suggesting that the lack of patient-centred care in so-called centres of excellence is responsible for the high uptake of "normalising" genital surgery. She calls for multi-disciplinary treatment teams to promote whole-person wellbeing in the long term.

In the final chapter of Part II, Carpenter thoughtfully contextualises the chapters in this section of the book while highlighting their relationship with globalised medical discourse. This chapter offers an overview of important subjects that permeate intersex studies such as nomenclature, global medicine, intersex and LGBT communities and universal human rights principles. Carpenter calls for the recognition of how Western narratives continue to dominate global medical practice and states the importance of future work that must be done to foreground the work of marginalised regions and populations. By identifying the diversity of voices and perspectives (some of which are not present in this collection), Carpenter seeks to recognise the impact of colonialism and colonial languages on the varying beliefs and value that give meaning to the lives of people with intersex variations.

Many of the chapters in the book can be read in conjunction with one another. De Clercq, Pellegrini and Dykstra all draw heavily on the arts in order to explore how intersex variations are represented in artistic modes such as film and literature. Film and literature play an important social and cultural role in society: they have long been a medium through which we can represent and reflect upon social and cultural events in different periods of time. Through these artistic representations of intersex variations, social discourses can be challenged and readers are able to reflect upon their own ideologies and assess their own response to intersex variations. Walker and Pellegrini both focus strongly on the study of narrative and the importance of narrative framing and linguistic choices when representing people with intersex variations, both in literature and in other kinds of text, such as medical reports. Jones' chapter makes a valuable contribution about authorship that links to both Walker's arguments about authorship and Das' focus on the lack of autonomy granted to people with an intersex variation in India. Jones' suggestion of a new methodological process for undertaking research with people with an intersex variation which participants control speaks to Liao's suggestion for the need for whole-person, people-centred care. People with intersex variations need to be treated with respect and need to have control over all research or medical treatment that they are party to. Carpenter and Jorden's interview clearly picks up on many of the different topics discussed elsewhere in the book: they touch upon the idea of genetic testing and termination of a foetus with an intersex variation, which is discussed in more detail in Meoded Danon's chapter on genetic determinism in Israel. They broach the idea of secrecy, which links to both Walker and Lih-Mei's chapters, and their discussion of social discourse connects well with Balocchi and Kehrer's chapters through their analysis of gender dichotomy and cultural beliefs and practices. Finally, their exploration of LGBT+ identities and third gender categories speaks to Qureshi's analysis of different cultural viewpoints in Pakistan. By bringing these chapters together into one collection, it becomes evident that there needs to be more recognition of the universal social and cultural discourse surrounding intersex variations and of how these in turn govern medical and legal decision-making.

What binds these contributions together unequivocally is the recognition that intersex human rights and intersex studies have a long way to go before intersex variations are accepted as naturally occurring variations that do not need to be erased. Across all the disciplines included in this volume, there is one unifying goal: to improve the lives and recognise the rights of people with an intersex variation or intersex experience. Through ongoing intersex studies, it is my hope that as a united front of activists, academics, researchers and practitioners, we may be able to change the representation and reception of intersex variations and that the 'intolerably hard' times (Hegarty & North, this volume) that people with intersex variations face today may become more tolerable in the future.

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PART I

Representing Intersex