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PhD Thesis, James Cook University.

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<https://doi.org/10.25903/7cjc%2Dcb95>

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Tripartite Sexuality Investigation between People with Intellectual Disabilities, Parents and
Service Providers in the Chinese social context.

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A thesis submitted for the degree of Doctor of Philosophy

(College of Public Health, Medical and Veterinary Sciences Division of Tropical Health and Medicine)

January 2023

Acknowledgments

This doctoral study has had a long period of gestation, with many people and institutions have made its completion possible. To complete a PhD, one requires determination, patience, and wisdom. For me, however, these qualities still remain very much in growth. I am fortunate to have had a PhD supervisory panel who possessed them in spades.

The searing constructive comments and criticism from Professor Matthew Yau, the primary supervisor of this thesis, immersed me into the world of qualitative research, encouraged me to take up the challenge of doctoral study in the area of sexuality. You have taught me to think more deeply and to theorise more sharply, and help me to refine, and to illustrate my thoughts and ideas. Without you, this study would never have been completed. Thank you for your support.

To my co-advisor, Professor Richard Franklin, you provide me chapters and verses about academic research. Your standpoint profited me immensely on how to explain a perspective to people coming from a different culture. You have blended constructive criticism and pastoral care and offered me a degree of patience that I did not always deserve. Thank you.

To my co-advisor, Professor Peter Leggat, thank you for your support and feedback. Your input always came at the right time and made me look at things from an insightful perspective. Your invaluable guidance is very helpful and has vastly improved the readability and accuracy of the manuscript. Thank you.

I must also acknowledge and thank my family for all the support and encouragement. To my better half, Karen, I owe my deepest thanks for your patience, acceptance, and love

during this long period of doctoral gestation. To my little lady and man, Sophie and Colin, who have always been there for me, but I have not been there enough. Thank you for your sacrifice that your father cannot be your playmate.

Finally, yet importantly, to the people with intellectual disabilities, parents and social services personnel who participated in this research, thank you for your involvement. Without your voices, private thoughts and experiences, this research would never have happened and would make much less sense.

Statement of the Contribution of Others - Publications

This is to certify that this thesis embodies original work undertaken by the candidate, except where contributions of others has been acknowledged in the publication. To my knowledge none of the papers has been submitted in support of any other award of this and other University or Institution.

A copy of each of the published papers, as they appear in the journal, can be found in the correspondent chapter list in the table below

Chapter	Publication	Role of the Authors	Authors Agreement with Contribution
Chapter 2 Literature review I	Lam, Y.K.A., Yau, K.S.M., Franklin, R., Leggat, P. (2019). The Unintended Invisible Hand: A Conceptual Framework for the Analysis of the Sexual Lives of People with Intellectual Disabilities. Sexuality and Disability, 37(2), 203-226. https://doi.org/10.1007/s11195-018-09554-3	Lam designed the study under the supervision of Yau, Franklin and Leggat. Lam performed the literature review search. The decisions on articles to be included/excluded received comments from Yau for any articles where there was uncertainty. Critical appraisal was completed by Lam and checked by Yau. Thematic analysis was conducted by Lam in consultation with Yau and Franklin. Lam wrote the first draft of the paper, including all figures and tables, with revision and editorial input provided by Yau, Franklin and Leggat.	Name: Prof. Matthew Yau Signature: Name: Prof. Richard Franklin Signature: Name: Prof. Peter Leggat Signature: Peter A Leggat Digitally signed by Peter A Leggat Date: 2022.11.09 15:28:14 +10'00'
Chapter 3 Literature review II	Lam, Y.K.A., Yau, K.S.M., Franklin, R., Leggat, P. (2021). Public Opinion on the Sexuality of People with Intellectual Disabilities: A Review of the Literature. Sexuality and Disability, 39(2), 395-419. https://doi.org/10.1007/s11195-020-09674-9	Lam designed the study under the supervision of Yau. Lam performed the literature review search. The decisions on articles to be included/excluded received comments from Yau for any articles where there was uncertainty. Thematic analysis was conducted by Lam in consultation with Yau. Lam wrote the first draft of the paper, including all figures and tables, with revision and editorial input provided by Yau, Franklin and Leggat.	Name: Prof. Matthew Yau Signature: 7 Nov 2022 Name: Prof. Richard Franklin Signature: 7 Nov 2022 Name: Prof. Peter Leggat Signature: Peter A Leggat Digitally signed by Peter A Leggat Date: 2022.11.09 15:28:34 +10'00'

Chapter 5 Result I	Lam, Y.K.A., Yau, K.S.M., Franklin, R., Leggat, P. (2022). Challenges in the Delivery of Sex Education for People with Intellectual Disabilities: A Chinese cultural-contextual analysis. <i>Journal of Applied Research in Intellectual Disabilities</i> . doi:10.1111/jar.13025	Lam designed the study under the supervision of Yau, Franklin and Leggat. Lam completed the interviews and transcribed the data to text. Lam completed the analysis, which was checked by Yau, Franklin and Leggat. Lam wrote the first draft of the paper, including all figures and tables, with revision, critical feedback, and editorial input provided by Yau, Franklin and Leggat.	Name: Prof. Matthew Yau Signature: v 2022 Name: Prof. Richard Franklin Signature: 22 Name: Prof. Peter Leggat Signature: Peter A Leggat Digitally signed by Peter A Leggat Date: 2022.11.09 15:28:57 +10'00'
Based on the comment made by examiner 1, this chapter now is chapter 7			
Chapter 6 Result II	Lam, Y.K.A., Yau, K.S.M., Franklin, R., Leggat, P. (2022). People with Intellectual Disabilities Struggle to have a Sexual Encounter: A Chinese Cultural Context Investigation. <i>Sexuality and Disability</i> , 40, 245–260. https://doi.org/10.1007/s11195-022-09733-3	Lam designed the study under the supervision of Yau, Franklin and Leggat. Lam completed the interviews and transcribed the data to text. Lam completed the analysis, which was checked by Yau, Franklin and Leggat. Lam wrote the first draft of the paper, including all figures and tables, with revision, critical feedback, and editorial input provided by Yau, Franklin and Leggat.	Name: Prof. Matthew Yau Signature: 2022 Name: Prof. Richard Franklin Signature: 2022 Name: Prof. Peter Leggat Signature: Peter A Leggat Digitally signed by Peter A Leggat Date: 2022.11.09 15:29:17 +10'00'
Based on the comment made by examiner 1, this chapter now is chapter 5			
Chapter 7 Result III	Lam, Y.K.A., Yau, K.S.M., Franklin, R., Leggat, P. (2022). Voices from parents on the sexuality of their child with intellectual disabilities: A socio-emotional perspective in a Chinese context. <i>British Journal of Learning Disabilities</i> . https://doi.org/10.1111/bld.12448	Lam designed the study under the supervision of Yau, Franklin and Leggat. Lam completed the interviews and transcribed the data to text. Lam completed the analysis, which was checked by Yau, Franklin and Leggat. Lam wrote the first draft of the paper, including all figures and tables, with revision, critical feedback, and editorial input provided by Yau, Franklin and Leggat.	Name: Prof. Matthew Yau Signature: 022 Name: Prof. Richard Franklin Signature: 2022 Name: Prof. Peter Leggat Signature: Peter A Leggat Digitally signed by Peter A Leggat Date: 2022.11.09 15:29:34 +10'00'
Based on the comment made by examiner 1, this chapter now is chapter 6			

Abstract

Sexuality covers a broad and complex cultural terrain involving sexual identities, beliefs, behaviours, and social organization. Every individual should be entitled with sexual autonomy but in fact sexuality is not only emerged as solely personal but also evolved from interactions with others in a particular sociocultural environment. It is commonly agreed that people with intellectual disabilities (ID) share the same human need for affectionate and intimate relationships as most other people, whereas parents and social services personnel are significant parties for promoting the sexual autonomy of people with ID. In the phase of literature review of this study, however, an “unintended invisible hand” generated by the power of Chinese Confucianism script was found. The “unintended invisible hand” has influenced the autonomy of sexuality of people with intellectual disabilities and was regarded as the force influencing the unconscious behaviours of all three parties. This invisible force controls the undeliberate tripartite reaction and demonstrates the interaction transmitted at the unspoken, and unconscious levels of communication.

Echoing to the above situations, the aims of this doctoral study were to: 1) provide an understanding of Chinese sexual attitudes and their influence on people with intellectual disabilities, 2) explore similarities and differences in the attitudes and concerns of parents of children with intellectual disabilities and social services staff in the context of handling the sexual needs of people with intellectual disabilities, and 3) investigate and explain the dynamic tripartite relationship of sexuality between people with intellectual disabilities, parents, and social services staff.

This study adopted the social science pluralistic approach, an application of more than one qualitative analytical methods, which allows a dual lens investigation to participants’ lived experiences and the meanings given to these experiences through their social interaction. For

this study, the dual lens are the Interpretative phenomenological analysis (IPA) and dramaturgy, as both perspectives entrench a connection with symbolic interactionism. These two independent but interlinked approaches are helpful in studying sexuality, particular in a Chinese context and exploration of individual experiences and the tripartite dynamics.

In total, 19 participants including people with mild ID, parents and social services personnel were recruited. Based on the framework of IPA and dramaturgy, study findings revealed the participants' experiences, obstacles, and underlying feelings regarding the sexuality of people with ID. These three underlying feelings: struggling, resignation, and shame, can be regarded as negative human emotions. However, none of the three participants groups had taken specific countervailing action or proactively advance people with intellectual disabilities' sexual autonomy.

Based on the analogy of invisible power, the tripartite groups in this study collaborated to perform a "Puppetry Front Stage Show". This puppetry show is a dramaturgical analogy indicating each party serves as a puppet controlled by the invisible power, the puppeteer, i.e., the overarching cultural values. Further on these findings, this study examined the functions of the tripartite dynamic in the context of Chinese cultural norms on sexuality. It further reveals the alliance through respecting cultural expectation and creating an equilibristic and harmonic mutual network, which is the priority and end goal of the entire social-cultural environment that the participants live in.

In conclusion, this is the first research to specifically explore the tripartite dynamic in the area of sexuality under the Chinese culture. This doctoral study also offers and outline of the potential strategies to promote the autonomy of sexuality of people with ID, the direction for future studies.

List of Publications Included in the Thesis

Five publications in peer-reviewed journals have been published. The published papers are attached in chapter 2, 3, 5, 6, and 7 respectively.

Chapter 2: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2019). The Unintended Invisible Hand: A Conceptual Framework for the Analysis of the Sexual Lives of People with Intellectual Disabilities. *Sexuality and Disability*, 37(2), 203-226.
<https://doi.org/10.1007/s11195-018-09554-3>

Chapter 3: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2021). Public Opinion on the Sexuality of People with Intellectual Disabilities: A Review of the Literature. *Sexuality and Disability*, 39(2), 395-419. <https://doi.org/10.1007/s11195-020-09674-9>

Chapter 5: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2022). People with Intellectual Disabilities Struggle to have a Sexual Encounter: A Chinese Cultural Context Investigation. *Sexuality and Disability*, 40, 245–260.
<https://doi.org/10.1007/s11195-022-09733-3>

Chapter 6: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2022). Voices from parents on the sexuality of their child with intellectual disabilities: A socio-emotional perspective in a Chinese context. *British Journal of Learning Disabilities*.
<https://doi.org/10.1111/bld.12448>

Chapter 7: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2022). Challenges in the Delivery of Sex Education for People with Intellectual Disabilities: A Chinese cultural-contextual analysis. *Journal of Applied Research in Intellectual Disabilities*.
[doi:10.1111/jar.13025](https://doi.org/10.1111/jar.13025)

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Chapter One

Prologue: the narration of the sexuality of people with intellectual disabilities

Chapter Overview

The central concern of this qualitative doctoral study is the tripartite dynamic between people with intellectual disabilities, parents, and social services staff focusing on sexuality issues concerning people with intellectual disabilities. Investigation of this tripartite relationship, incorporating consideration of cultural particularities, generates numerous, often complex, questions depending on the peripheral goals and interests of the parties involved, and which are not always mutual.

Human sexuality encompasses individuals' sexual knowledge, beliefs, attitudes, values, and behaviours (Greenberg et al., 2017). It is one of the most important aspects of human life associated with identification, personal role, pleasure, and intimacy (Kijak, 2013). However, both in the author's clinical experience and previous research findings (Kramers-Olen, 2016), some constraints, such as restrictive attitudes and overprotection (Parchomiuk, 2022) have been imposed on people with intellectual disabilities. The impact of these constraints is that people with intellectual disabilities may not enjoy the same autonomy as their counterparts without disabilities to enjoy a sexual life or establish intimate relationships.

This chapter sets out the key concepts used in this study: sexuality, characteristics of people with intellectual disabilities, and the research context - the Chinese socio-cultural

environment and the key features of social services in Hong Kong. Subsequently, the aims of research will be justified. This chapter concludes by setting out the structure of the thesis and summaries of each chapter.

Key Concepts Defined

Sexuality is the core concept of this thesis. The foremost group of people connected to this concept is people with intellectual disabilities. The following section delineates the essential concept of sexuality and its connection with disabilities. In addition, a brief explanation of the characteristics of people with intellectual disabilities and the challenges they face in pursuing sexual and intimate relationships is provided.

Human Sexuality

Sex, after all, should be one of the primary areas of concern for all human beings. Without it, there could be no continuation of the human species. Over the centuries, people have attempted to define, discuss, and understand it (Yarber & Sayad, 2019). For some, sexuality can be regarded as a form of physical contact for the purpose of reproduction. While others, sexuality refers to the feelings generated when an individual is attracted to another person. Indeed, human sexuality is a part of our total personality. It comprises the interrelationship of multi-dimensional aspects encompassing anatomy, physiology, and biochemistry of the sexual response system. It involves knowledge, beliefs, feelings, and behaviour of individuals. It connects to personal identity, orientation, roles, personality, relationships, and spiritual and moral concern (Hill, 2007). Ultimately, this intertwined, dynamic relationship formulates an individual's total sexuality (Greenberg & Bruess, 2017).

To be sexually active, a personal decision has to consider factors. Biological, sexual arousal and orgasm are mediated by complex physiological functions. Psychologically, our body image and feelings of self-worth may help to approve, or inhibit this arousal (Au et al., 2019). Further, our culture constructs the sense of what is attractive - height, weight, hair style, skin tone (Adolmanafi et al., 2018). Religious beliefs, legal and ethical considerations also affect people's sexual undertakings (Abbot et al., 2016). Indeed, people receive messages about sexuality from their family, friends, teachers and even clergy. Messages about sexuality can be subtle, disguised or explicitly channelled via movies, television programs, and nowadays, the internet (Hill, 2007).

Sexuality and culture

Unlike the concept of mathematics or physics, human sexuality is surrounded by a vast array of taboos, fears, prejudices, and hypocrisy (Yarber & Sayad, 2019). Alluding to David Hilbert, a German mathematician, mathematics knows no races or geographic boundaries; the cultural world is one country. But this "one country" does not apply to sexuality. In the Hindu tradition, sexual rites can be imagined as divine incarnations of Shakti and the Hindu god Shiva (Chakraborty & Thakurata, 2013). In the Judeo-Christian tradition, sex is equated with sin, the original sin occurring in the Garden of Eden, and many sexual practices became crimes punished by ecclesiastical courts (Duddle, 1988). In Chinese culture, sexual dysfunction may result from "yin-yang" imbalance which the balance can be restored by having soup with animal genital parts (Dan et al., 2017). Culture moulds and shapes people to celebrate sexuality at one time but condemn it at other times. Sexuality is linked not only with intimacy and pleasure but also with shame, guilt, and discomfort (Litam & Speciale, 2021).

Culture is possibly the most powerful influence shaping how we feel and behave sexually. Although a significant amount of time has passed since the end of the Victorian era, and the counterculture has attempted to shift values and attitudes about sexuality, many traditional sexual beliefs and attitudes continue to influence us. These include the belief that men and women are “naturally” sexually aggressive and passive, respectively (Yarber & Sayad, 2019). The immense diversity of sexual behaviours across cultures and times immediately calls into question the appropriateness of labelling these behaviours as inherently natural or unnatural, normal or abnormal. However, heteronormativity is believed as the most pervasive view of sexuality in many cultures. People regard heterosexuality as normal, natural, and superior to all other expressions of sexuality (Robinson, 2016). These norms are part of the cultural air we breathe, and, like the air, they are invisible. People have learned their cultural rules so well that they have become a “natural” part of their personality, or like “second nature” to everyone.

People with Intellectual Disabilities

The terminology referring to intellectual disabilities has changed over time. In the early 1900s, labels for individuals with intellectual disabilities included “imbecile”, “feeble-minded”, “idiots”, and “mentally deficient” (Roth et al., 2019). In 1952, the American Psychiatric Association (APA, 1952) published the first Diagnostic and Statistical Manual of Mental Disorders (DSM) and classified this condition as “chronic brain syndrome with mental deficiency” (p. 14) and “mental deficiency” (p. 23). In 1959, the term “mental retardation” was first introduced by the American Association of Mental Deficiency (Fredericks & Williams, 1998), and this term was further incorporated as a diagnostic term in the second edition of the APA manual, DSM-II. Not until publication of DSM-III in 1980 did the APA (1980) acknowledge that “mental retardation” did not solely include a deficit in intellectual

functioning but also impairment in adaptive skills. From 1980 through the early 2000s, this remained the definition and conceptualisation of “mental retardation”. In 2010, the World Health Organization and the American Association on Intellectual and Developmental Disabilities (AAIDD), formed working groups to prepare for proposed changes in the application of the term “Intellectual Developmental Disorder”. The term IDD was adopted and included in parenthesis in the DSM5 ID (IDD), underscoring the conceptualisation of ID as a brain-based health condition and not as a disability. In contrast to the DSM5, the AAIDD defines ID as a “disability” and not as a “health condition” with a primary focus on the individual’s functioning, adaptive behaviour and support needs (Bertelli et al., 2016).

Consequently, this thesis will employ the term “people with intellectual disabilities” as standardized terminology. Based on the statistical distribution of IQ scores, the classification of the people with intellectual disabilities commonly includes four categories: (1) mild intellectual disabilities refers to an IQ range of 55–69, (2) moderate intellectual disabilities to an IQ range of 40–54, (3) severe intellectual disabilities to an IQ range of 25–39, and (4) profound intellectual disabilities to an IQ below 25 (McDermott et al., 2007). This categorization often indicates the level of an individual’s dependency needs and expressive language capability (Gentile, 2019). According to Gentile (2019), generally, individuals with mild intellectual disabilities live independently in a supported residential situation with family or direct care professionals and participate in life-long supported employment. Individuals with moderate intellectual disabilities will most often need varying levels of support from their family or community services. Their limited expressive language skills typically restrict them from communicating subjective complaints about their mental health and medical illnesses. Individuals with severe and profound intellectual disabilities are likelier to have very high

levels of dependence on external support and have associated medical conditions requiring assistance and care for all aspects of living.

Sexuality and People with Intellectual Disabilities

People with intellectual disabilities most often have difficulties with major life activities such as language, mobility, learning, self-help, and independent living (Patel et al., 2020). People with mild or moderate disabilities have the potential to learn to behave appropriately, protect themselves from abuse, and understand the basics of reproduction. Some even manage to have romantic relationships, marry, work, and raise families with little assistance (Yarber & Sayad, 2019).

The health of people with intellectual disabilities is likely to be compromised by inequity and inequality, and thus they are susceptible to health loss (Barr et al., 2019a). People are not always comfortable with the idea of people with intellectual disabilities having a sexual identity, let alone engaging in consensual sexual activity (Barr et al., 2019b). For example, throughout adolescence, young people with intellectual disabilities continue to tussle with their identity and the opportunity to make decisions about sexuality and relationships because significant others assume control of their lives make decisions for them (Lam et al., 2019). Often the challenge they face is that being classified as having intellectual disabilities dominates their sexual identity, as their caregivers and society inhibit their sexual exploration and capacity to manage risk (Wilkinson, et al., 2015; Medina-Rico et al., 2018). Some parents oppose the implementation of sex education. They perceived that the curriculum will “put ideas into the heads” of their children with intellectual disabilities (Bialystok, 2018; Schaafsma et al., 2017). However, it is more likely that such ideas have already been disseminated through the combination of explicit media, internet images and the effects of increased hormonal output.

In addition, some people have perceived that people with intellectual disabilities required protection from sexuality because they are considered “eternal children” (Yau et al., 2009; Björnsdóttir et al., 2017) and have no sexual feelings (Taylor, 2012).

The disability rights movement is a global social effort that aims to provide equal opportunities and rights for all people with disabilities. When focusing broadly on rights, the gender and sexuality of people living with a disability can easily be rendered invisible or subjugated to other seemingly “higher order” issues (Higgin, 2010). It is important to break down barriers preventing people with disabilities from enjoying everyday living like other citizens. Indeed, people with intellectual disabilities share the same human need for affectionate and intimate relationships as their peers without a disability (Rushbrooke et al., 2014a). People with mild or moderate intellectual disabilities are capable of and show a desire for sexual and intimate relationships (Fitzgerald & Withers, 2013; Schaafsma et al., 2017) and are also able to talk about sexual intercourse with a loved one as a mutually enjoyable experience (Fitzgerald & Withers, 2013). Most people desire love and a sense of connection with others; they wish to be safe, to learn, to lead a meaningful life, to be free from ridicule and harm, to be healthy, and to be free from poverty, and in this respect, people with intellectual disabilities are no different to any of us (Lam et al., 2019). Research clearly identifies the importance of addressing sexuality in people with intellectual disabilities not only at the personal level but also including their family and support networks (Medina-Rico et al., 2018).

Research Context

Research reveals that parents and the welfare system are two significant systems that influence opportunities for people with intellectual disabilities to engage in intimate

relationships and express their sexual needs (Morales et al., 2011; Medina-Rico et al., 2018; Parchomiuk, 2022). In addition, culture is an elusive lever that shape and form unspoken behaviours, mentality, and social patterns in wide-ranging and durable ways (Gurung, 2019; Reeta, 2021). Therefore, it is essential to consider Chinese family culture, Chinese sex culture, and the social and education system for people with intellectual disabilities in Hong Kong, where the study took place.

Chinese family system

Historical traditions coupled with rapid social changes shape contemporary Chinese behaviours. From the revolution between 1949 and 1978, post-Mao reforms to the present time, China has experienced multiple social revolutions and major transitions that have eroded the traditional functions and authority of the family. Despite these, in the Chinese family system, marriage and childbearing remain the dominant features of societal rule and relational harmony (Yao et al., 2018; Yu & Xie, 2021). Moreover, there is considerable evidence of the significance Chinese parents place on their children's education, even as a family investment (Lei & Shen 2015; Li & Xie 2020).

Filial piety, understood as adult children's duty to support aged parents, has remained a core cultural value and patriarchal principle for the intergenerational contract in Chinese families (Bedford & Yeh, 2019). Filial piety is fundamental in Confucian philosophy that still serves as a moral compass for attitudes, the duty to take good care of parents, and is the driving force of family caregiving (Lai, 2010). Family caregivers frequently perceive care for people suffering from illness or disabilities as fulfilling their filial obligations, eventually making the family the primary caring system (Liu et al., 2022).

The patriarchal principle is also a dominant ideological characteristic of Chinese social tradition. That primary stems from a society-wide generalisation of a whole set of family norms, values and customs, and creed of familial continuity and prosperity, with the family and clan as concrete entities bonded by blood or marital relations (Harrell & Santos, 2017). For example, when a son takes over the management of a family business from an aged father, the father should remain as the chairman of the managerial board as a symbol of the continuity of power from the senior generation. Further, to show veneration, older family members should be the representative of the household in rituals and ceremonies. Put simply, a family's stability and prosperity are impossible without harmonious family relationships (Zhang & Constantinovits, 2016).

From a Confucian perspective, the family is both a unit of social structure and the foundation of the entire value system (Liu & Stening, 2016). Contrasting with the “city-as-state society” of ancient Greece, ancient China is sometimes described as a “state-as-family society” (Feng, 2012). The Chinese word “guójiā”, equivalent to the English term “country”, contains the Chinese character for family. Thus, in Chinese national ideology, the family and state are inseparable.

The notion of harmony in Chinese culture extends to both society and country, as expressed in the Chinese idioms, “all things flourish in a harmonious family” and “we make a big fortune in a harmonious atmosphere”. The West cherishes individual autonomy and political pluralism, whereas, in China, the government craves harmony and social order, the two tenets of Confucian thought (Bennett, 2021). Although these ideas sometimes inhibit individual desires, ideas, hobbies, interests, etc., harmony can or even must be accepted at the

familial, social, and national levels (Chen, 2019). In sum, given the domination of cultural mores and Confucian ethics, marriage and childbearing are the duty of Chinese people. Maintaining harmony within personal associations and state-society relations in everyday life is also an important obligation with which the Chinese must comply (Gao & Zhao, 2018; He et al., 2020).

This doctoral study took place in Hong Kong. More than 100 years as a British colony from 1842 to 1997 crafted Hong Kong's health and social care system within a market-orientated economic framework (Kong et al., 2015). Lifestyles in Hong Kong are urban-centric and cosmopolitan because of the proportion of the population whom the western tertiary education system have been socialised. However, the core values (e.g., hard work, family duty, and the centrality of family in promoting social harmony), originating in Confucian philosophy, remain cherished and rooted in the mindset of Hong Kong Chinese (Yiu et al., 2020). The younger Hong Kong generation commonly performs their "duty" according to the doctrine of filial piety (Zhang, et al., 2020). Under the dominant cultural umbrella, Hong Kong parents would usually control their children's life choices. Although those constraints are noticeable, harmony, or consonance within a family, is still afforded primacy.

Chinese Sex Culture

Sexuality in China is woven into the political fabric; sexual life is embedded in everyday life and is always lived within wider social contexts (Jackson & Scott, 2010). At home, most parents find sex is a subject too "embarrassing and awkward" to talk about (Steinhauer, 2016). Within Hong Kong society, discussion on sexuality remains dominated by authoritarian societal expectations of heterosexual marriage (So & Cheung, 2005). Same-sex

relationships defile the core of Confucianism and continue to be stigmatized in China and Hong Kong (Kong, 2016; Suen, 2016).

The de-coupling of sex from reproduction has been seen, in the western context, as creating the precondition for sex as leisure/recreation and, ultimately, with many shifts over a century, making possible the acceptance of alternatives to heterosexuality (Seidman, 2015). It is not easy to see the same path in Chinese culture. Sexuality in China is interconnected to neoliberal and authoritarian styles of governance (Guo, 2010; To, 2015). Echoing the ideology placing a premium on female virginity, many young Chinese women intend to engage in sexual intercourse only with a future husband (Wang & Ho, 2011; Wang, 2017; Zarafonetis, 2017).

Being normal, behaving normally or complying with the sexual doctrine, a form of “collective unconscious”, is crucial to Chinese people. (Huang & Pan, 2009; Ho et al., 2018). Hong Kong maintains the heritage of British colonialism, while a conservative sexual culture is reinforced by a strong Christian influence (Ho & Hu, 2016). The legitimated form of sexual expression in China and Hong Kong is heterosexual, marital, and monogamous (Ho et al., 2018). To be an ideal sexual citizen, people should exercise self-restraint in avoiding sex outside marriage and seek harmony and balance within it, while marriage has a strong association with childbearing. It is not surprising, therefore, that the central aspect of Chinese sexual culture is conformity to marriage and procreation (Jeffrey & Yu, 2015). As the Chinese concept centres on the family and considers the family the foundation of the state, violation of the sexual doctrine can be regarded as disrupting the core idea of harmony, or even threatening social stability (Sigley, 2006).

Local Services for People with Intellectual Disabilities

Hong Kong health care and social services have evolved from providing emergency relief in the early years to their present role providing a diversified range of professional social welfare services. Through a comprehensive territory-wide network, health care and social services also sustain a non-contributory social security safety net for caring for various needy groups (Nip, 2010).

Rehabilitation policy in Hong Kong aims to develop the physical and mental capacities of persons with disabilities and their ability to integrate into the community (Social Welfare Department, 2005a). The Hong Kong Social Welfare Department (SWD) provides three types of rehabilitation services for children with intellectual disabilities from birth to the age of six years. The Early Education and Training Centre (EETC) aims to provide assessment and training programs for both the child with intellectual disabilities and their family. The SWD offers the Integrated Programme in Kindergarten-cum-Child Care Centre to facilitate child with mild disabilities integrates into mainstream education and society. Lastly, the Special Child Care Centre (SCCC) for children with moderate to severe disabilities aims to facilitate their growth and development and to help them prepare for primary education in a special school.

Between the ages of 6 and 16, most children with intellectual disabilities attend a special school to continue their learning. In the 2018/2019 school year, Hong Kong had 60 special schools catering for 7,939 students (Ho & Lam, 2020). According to Ho & Lam, 41 schools catered for around 6000 students with mild to severe intellectual disabilities. In addition, an integrated education (IE) scheme promoting the education of children with intellectual disabilities in mainstream schools was initiated in Hong Kong in 1998. In the 2016/2017 school

year, 671 and 907 children assessed with mild intellectual disabilities as high functioning students, enrolled in mainstream primary and secondary schools, respectively. The principle of including all students with diverse needs and providing them with equal learning opportunities has been mandated or experimented with in many countries (Lo et al., 2019). Hong Kong is no different. Since 2001, the government Education Bureau committed to the principle that all students should learn under “one curriculum framework for all.” The policy aims to ensure that all students, including children with special educational needs, have equal educational opportunities with suitable adjustments to the overall curriculum framework (Education and Manpower Bureau, 2005). In essence, learners with and without disabilities are exposed to and taught the same curriculum with universal aims and instructional objectives to fulfil each learner’s life-long goals in an inclusive community (Lian et al., 2007). In other words, the same framework of sex education in Hong Kong applies to both the mainstream curriculum and people with intellectual disabilities (Schaafsma et al., 2015).

Subsequent to graduation from school, most young people with intellectual disabilities are referred to social services to receive continuous support. In 2009, the SWD has strengthened community support services to assist people with intellectual disabilities remain in a familiar environment by setting up 16 one-stop District Support Centres (Social Welfare Department, 2009). Moreover, day training and vocational rehabilitation places have strengthened the daily living skills of people with intellectual disabilities and equipped them with job skills to enhance their employability. The SWD has offered seed money to NGOs to set up small businesses to provide open employment opportunities for people with intellectual disabilities (Social Welfare Department, 2005b). Lastly, residential care services are provided for people with intellectual disabilities who cannot live independently or cannot be adequately cared for by their families.

Social services orientation and sex education in Hong Kong.

In the Hong Kong social services sector, with the pervasive trend of managerialism, more “market-oriented” principles, have been adopted, including emphasizing the 3E and 3M principles (economy, efficiency, effectiveness; and market, management, measurement) (Chui et al., 2010). In 1999, the government kick-started a scheme to contract welfare services as an alternative to the existing model of continued subvention to NGOs. Emphasizing service delivery productivity, privatization and marketization strategies have been introduced into the running of public services, including higher education. In this context, higher education has mushroomed with more training programs offering undergraduate and postgraduate degrees with growing interest in health care and social services training (Chui et al., 2010; Lo, 2014). However, research later revealed that client-centred, case management practice was not taught systematically, sufficiently, or with in-depth practice experiences in social services education in Hong Kong (Xun, 2019).

One study identified schoolteachers and mass media as the two most important sources of sex knowledge in China (Zhang et al., 2007). According to Zhang, teachers and parents were often asked about fewer taboo topics such as puberty but not about more sensitive topics such as sexuality, sexual behaviours, or sexually transmitted infections (Zhang et al., 2007). In Hong Kong, the Family Planning Association of Hong Kong (FPAHK), a local public statutory organization, began to promote sex education in the 1960s. Twenty years later, the Hong Kong Education Department published guidance on sex education in secondary schools with recommendations on topics, resources, and references for promoting relevant programs. Subsequently, in 1987, 1990 and 1994, the Education Department’s Advisory Inspectorate conducted three surveys investigating the implementation of the sex education guidelines in schools. The results were disappointing, revealing no improvement in sex education in schools

(Fok, 2005). The guideline was revised further in 1997 but as an advisory document only (Leung et al., 2019) and has not been revised subsequently (Cheng, 2018).

Regarding the content of sex education in Hong Kong, Ng (1998) has commented that the guidelines were deeply skewed towards moral indoctrination and family relationships, sexual anatomy, and physiology but limited or entirely omitted discussion on sexual orientation, prostitution, and erotic media. Other studies have also pointed out that the 1997 guideline was strongly biased toward teaching young people socially accepted morality (Ho & Tsang, 2002). Most schools claimed that sex education was delivered to some grades but not to the entire school (Cheng, 2018). Education in Hong Kong is regarded as examination driven, and the examinations are structured to dominate the style and content of learning in the classroom. Moreover, sex education is often an ungraded subject in the syllabus. In this circumstance, sex education is usually regarded less important (Fok, 2005). Even in the field of research, sexuality issues have been dominated by a bio-medical model aimed at producing the ideal socialist citizen (Wong, 2016).

Social workers, nurses, trainers, and health and social care practitioners certainly have a role in communicating sexuality messages to people with intellectual disabilities. The sexuality of people with intellectual disabilities, nevertheless, was found to be viewed only through the narrow perspective of biology, prevention of abuse or pregnancy, but not on empowerment for an active sexual life and sense of fulfilment like everyone else (Tepper, 2000; Turner & Crane, 2016a). Allowing people with intellectual disabilities to engage in sexual activity was perceived as a deviant condition that possibly induced fear among social service staff (Alphen et al., 2011). Indeed, research revealed that social and healthcare professionals

did not proactively discuss sexuality issues with people with intellectual disabilities (Dyer & Nair, 2013).

Research Aims

There is no doubt that parents are likely the most influential and consistent coaches of sexuality for people with intellectual disabilities. However, the above discussion raises questions about how the Chinese sex culture moderates the interaction between people with intellectual disabilities and their parents. Under the dominant Chinese family system, do parents impose restrictions on their children with intellectual disabilities regarding sexual expression or the desire for an intimate relationship? When these situations fuse with a social care system that does not acknowledge the importance of sex education, what is the impact on the autonomy about sexuality of people with intellectual disabilities?

A qualitative investigation was proposed to address these questions, with the following aims:

- a) To provide an understanding of Chinese sexual attitudes and their influence on people with intellectual disabilities.
- b) To explore similarities and differences in the attitudes and concerns of parents of children with intellectual disabilities and social services staff in the context of handling the sexual needs of people with intellectual disabilities.
- c) To investigate and explain the dynamic tripartite relationship between people with intellectual disabilities, parents, and social services staff in handling the sexual needs of people with intellectual disabilities.

Thesis Structure

In this study an iterative process was applied to analysis to gain insights into aspects of meaning in sexuality situated in Chinese culture. Iteration refers to repeatedly revisiting the data, moving back and forth between concrete bits of data and abstract concepts, inductive and deductive reasoning, and description and interpretation (Kekeya, 2016). This flexible approach to data analysis, derived from Interpretative Phenomenological Analysis (IPA), helped to prevent the author from trying to force data into pre-existing schemas and, consequently, assisted the analytic process in constructing an authentic account of participants' the insights and experiences.

The study focuses on the tripartite relationship among three parties, resulting in a necessary conceptual overlap between some of the findings in this thesis. For example, chapter 6 was based on the phenomenon of the well-behaved child stemming from categories presented in chapter 5. This means that, to some extent, the findings presented in the latter chapters of this thesis do not serve as stand-alone analyses. Instead, they offer a progression of the analyses outlined in the previous chapters.

At the commencement of this PhD journey, the author intended to produce a conceptual framework to explain the sexuality of people with intellectual disabilities in the Chinese context. It is hard to claim having done so. As the research evolved, insight and awareness about the complexity and diversity of participants' experiences, and the socio-cultural context, increasingly persuaded the author of the impossibility of this. The investigation was a dynamic, layered one and shed light on several elements of this process. This is not to claim that the thesis research does not carry either theoretical or clinical importance. Instead, it emphasizes the multi-faceted and variable nature of the tripartite interaction between the participants and

its connection with the socio-cultural environment. As a healthcare practitioner in the field of rehabilitation, this valuable research journey has highlighted that by acknowledging the complexity, a responsive, meaningful, and person-focused support system/mechanism for the autonomy of people with intellectual disabilities regarding sexuality can be derived.

Overview of thesis chapters and content

Chapter 1 (this chapter) offers an overview of the thesis. It provides a definition of sexuality and the characteristic of people with intellectual disabilities, the contextual issues, motives, and rationale for undertaking the study. The chapter concludes with a summary of the thesis content and structure.

Chapter 2 examines the literature regarding the perspectives of people with intellectual disabilities on their life and attitudes toward sexuality. It details the existing evidence demonstrating that people with disabilities have the same needs for affectionate and intimate relationships as others.

Publication

Lam, Y.K.A., Yau, K.S.M., Franklin, R. C, Leggat, P. A. (2019). The Unintended Invisible Hand: A Conceptual Framework for the Analysis of the Sexual Lives of People with Intellectual Disabilities. *Sexuality and Disability*, 37(2), 203-226.
<https://doi.org/10.1007/s11195-018-09554-3>

Chapter 3 investigates evidence on public views of the sexuality of people with intellectual disabilities. Participants' age and gender were found to be crucial factors influencing public attitudes towards sexuality issues of people with intellectual disabilities. In general, the public acknowledged that people with intellectual disabilities were not asexual. In

addition, they held a more accepting attitude towards the sexuality of people with intellectual disabilities compared to family or social and health care staff.

Publication

Lam, Y.K.A., Yau, K.S.M., Franklin, R. C., & Leggat, P. A. (2021). Public Opinion on the Sexuality of People with Intellectual Disabilities: A Review of the Literature. *Sexuality and Disability*, 39(2), 1-25. <https://doi.org/10.1007/s11195-020-09674-9>

Chapter 4 explains the conceptual framework, methodology, and associated processes for data collection and analysis undertaken in this study. The chapter concludes with an overview of the processes built into the research design to promote analytical rigour and maintain ethical conduct.

Chapter 5 presents the first of three finding chapters related to this thesis. This chapter focuses on the experiences of people with intellectual disabilities in expressing their needs for sexuality and intimate relationships. This chapter examines the situations of people with intellectual disabilities asking for autonomy on sexuality and the opportunity to establish intimate relationships. People with intellectual disabilities generally experience rejection or restriction from parents and social service staff. It employs the dramaturgical perspective to analyse the struggle and compromise of people with intellectual disabilities.

Publication

Lam, Y.K.A., Yau, K.S.M., Franklin, R. C., & Leggat, P. A. (2022). People with intellectual disabilities struggle to have a sexual encounter: a Chinese cultural context investigation. *Sexuality and Disability*, 40. 245–260. <https://doi.org/10.1007/s11195-022-09733-3>

Chapter 6 presents the findings from the group of parents with a child with intellectual disabilities. This chapter examines how parents react to their child's desire for intimate relationships and their experiences in dealing with their child's sexual need. The findings highlight the challenges associated with the constraints imposed by Confucianism. It further applies the dramaturgical perspective to explain parents' front stage and backstage behaviours.

Publication

Lam, Y.K.A., Yau, K.S.M., Franklin, R. C., & Leggat, P. A. (2022). Voices from parents on the sexuality of their child with intellectual disabilities: A socio-emotional perspective in a Chinese context. *British Journal of Learning Disabilities*.
<https://doi.org/10.1111/bld.12448>

Chapter 7 examines social services staff approaches to handling the sexuality of people with intellectual disabilities in different service settings. It highlights the challenges associated with delivering sex education, handling conflict and tension among working team members, and demands from parents of people with intellectual disabilities. It further argues that the collectivistic culture moderated social service staff's feelings of resignation and how they cooperated with other stakeholders.

Publication (accepted 7 July 2022)

Lam, Y.K.A., Yau, K.S.M., Franklin, R. C., & Leggat, P. A. (2022). Challenges in the Delivery of Sex Education for People with Intellectual Disabilities: A Chinese cultural-contextual analysis. *Journal of Applied Research in Intellectual Disabilities*.
<https://doi.org/10.1111/jar.13025>

Chapter 8 provides an integrated analysis of the findings. Chinese sex culture is explained in detail again, and its connections with and influences on the three groups of participants clearly explained. Subsequently, the dramaturgical perspective is employed as the theoretical framework to investigate the tripartite interaction. The dramaturgical perspective provides the insight that handling sexuality issues of people with intellectual disabilities is a form of impression management, echoing the invisible demand imposed by Chinese culture.

Chapter 9 discusses the implications of the study findings for the provision of sex education and support to people with intellectual disabilities. It outlines how subtle shifts in practice can potentially encourage sexual autonomy of people with intellectual disabilities. It also analyses the important function that social services initiatives such as anti-stigmatization and sex education could enhance the sexual lives of people with intellectual disabilities. Lastly, this chapter outlines the strengths and limitations of the study and a summary of the thesis.

Chapter Conclusive Summary

This doctoral study situates the sexuality of people with intellectual disabilities into the relationship with other two groups of participants: parents, and social services staff. It explores, in a Chinese context, how the experience of living in a Confucian culture influences attitudes towards sex and the dynamic interaction among the tripartite groups. The thesis helps advance caring and social services professionals' sex education work and advocacy of the autonomy of people with intellectual disabilities regarding sexuality.

Chapter Two

Exploration: the experience of sexuality in people with intellectual disabilities

Chapter overview

Chapter 2 contains the literature review to discuss the knowledge gaps for this doctoral study and to recognize the need of sexuality of people with intellectual disabilities. By reviewing the qualitative papers based on the perspective of people with intellectual disabilities, this chapter identify 1) sexual behaviours of people with intellectual disabilities; and 2) possible factors influencing the experience of sexuality of people with intellectual disabilities. Finally, the direction for future study is presented.

Chapter structure

This section is based on a publication (Publication 1) in the *Sexuality and Disability*. Starting from the next page, the published paper will be presented as in the format of the journal article. Subsequently, a chapter conclusive summary would be provided.

Citation of the paper: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2019). The Unintended Invisible Hand: A Conceptual Framework for the Analysis of the Sexual Lives of People with Intellectual Disabilities. *Sexuality and Disability*, 37(2), 203-226. doi:10.1007/s11195-018-09554-3



The Unintended Invisible Hand: A Conceptual Framework for the Analysis of the Sexual Lives of People with Intellectual Disabilities

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Abstract

People with intellectual disabilities (PID) share the same needs for affectionate and intimate relationships as other people. In this study, a review of the literature was performed to (a) examine the opinions reported in the peer-reviewed literature regarding the sexual experiences of PID and (b) identify factors that contribute to the promotion or restriction of sexual expression by PID. Sixteen qualitative articles were identified from electronic databases and reviewed. People with PID were found to exhibit the same spectrum of sexual life as the general population, and three major themes were identified: abstinence, regulation, and autonomy. Some PID preferred to abstain from sex, whereas others considered engagement in sexual activity to have a hand that affects and influences the rights of PID to engage in sexual activity. Further empirical research on the empowerment of sexual expression of PID and the formation of the unintended invisible hand is needed, as this will provide information to families and welfare systems and thus enhance the self-determination and rights of PID to pursue sexual expression and satisfaction.

Keywords Intellectual disabilities · Parents and service providers · Sexuality · Sexual expression · Self-determination · Hong Kong

Introduction

Most people consider sexual relationships to be one of the most significant needs in their lives, and people with intellectual disabilities (PID) and their counterparts of people without disabilities share the same human need for affectionate and intimate relationships [1]. In recent decades, the concepts of normalization and social role valorization, particularly regarding the rights of PID, have emerged in both Western and Eastern societies (e.g., United States, Australia, and Hong Kong) [2]. According to the American Association on

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Intellectual and Developmental Disabilities (AAIDD), however, PID are often perceived as asexual and as not requiring loving or fulfilling relationships; in other words, their individual right to sexuality is denied [3]. Scholars have also argued that due to various perceptions, the rights of PID to maximize their own potential in terms of sexual health (e.g., dating, entering a relationship, sexual intercourse, or procreation) were limited and not affirmed, defended, or respected as such rights would be for individuals without PID [3, 4]. In fact, the sexuality of PID should not be considered only through the narrow perspective of abuse or pregnancy prevention, but rather through the lens of empowerment to achieve an active sexual life and the sense of fulfillment made available to everyone else [5, 6].

The collection of opinions from PID is considered essential to understanding the sexual lives of PID and informing their families, service providers, and policymakers about their needs [7]. This information could benefit families, service providers, and policymakers by enabling them to recognize existing limitations and align their support with the sexual needs of PID. Based on this notion, this current literature review aims (a) to review the opinions reported in the peer-reviewed literature and thus enable an understanding of the sexual experiences of PID and (b) to identify factors that contribute to the promotion or restriction of sexuality among PID.

Methods

Search Strategy Used in this Study

Literature searches were conducted in June 2017. Although the term “intellectual disability” is increasingly used, historically the terms “mental retardation” and “mental handicap” were commonly used for the population of PID [8]. To ensure that most relevant papers would not be excluded from the search results, the term “learning disability” was also considered. The following keywords were selected to meet the aims of the study: *intellectual disability*, *mental retardation*, *mental handicap*, *learning disability*, *sexuality*, *sexual behavior*, *sex education*, *sexual relationship*, *sexual health*, and *masturbation*. All articles were selected from peer-reviewed journals using the following online databases: ERIC, Ovid Medline, PsycARTICLES, PsycINFO, CINAHL, Science Direct and Social Sciences Citation Index (Fig. 1).

The search covered the period from 2007 to 2017 and identified a huge number (> 3000) of potential papers that might match the aims of the review. The search results were then filtered to yield a final list of articles for review. The review process used the following inclusion criteria: (1) publication in English; (2) focus on issues related to sexuality, sexual life, and relationships, and (3) collection of data from PID. This filter strategy initially identified 30 potential papers, including 4 quantitative and 26 qualitative studies.

To finalize the list for review, all potential papers were reviewed. The paper selection process, which was based on the PRISMA flow chart [9], involved the repeated reading and analysis of potential paragraphs and data. First, four quantitative papers and seven qualitative papers focused on puberty, HIV prevention, sexual violence and prevention, or legal knowledge about sexuality, which did not meet the second criterion of this review. Therefore, these papers were excluded from the review.

To ensure that the remaining 19 qualitative papers were suitable for analysis, the Critical Appraisal Skills Program (CASP) was used to evaluate the quality and relevance to the study of each potential paper (see Table 1). Responses to questions included in

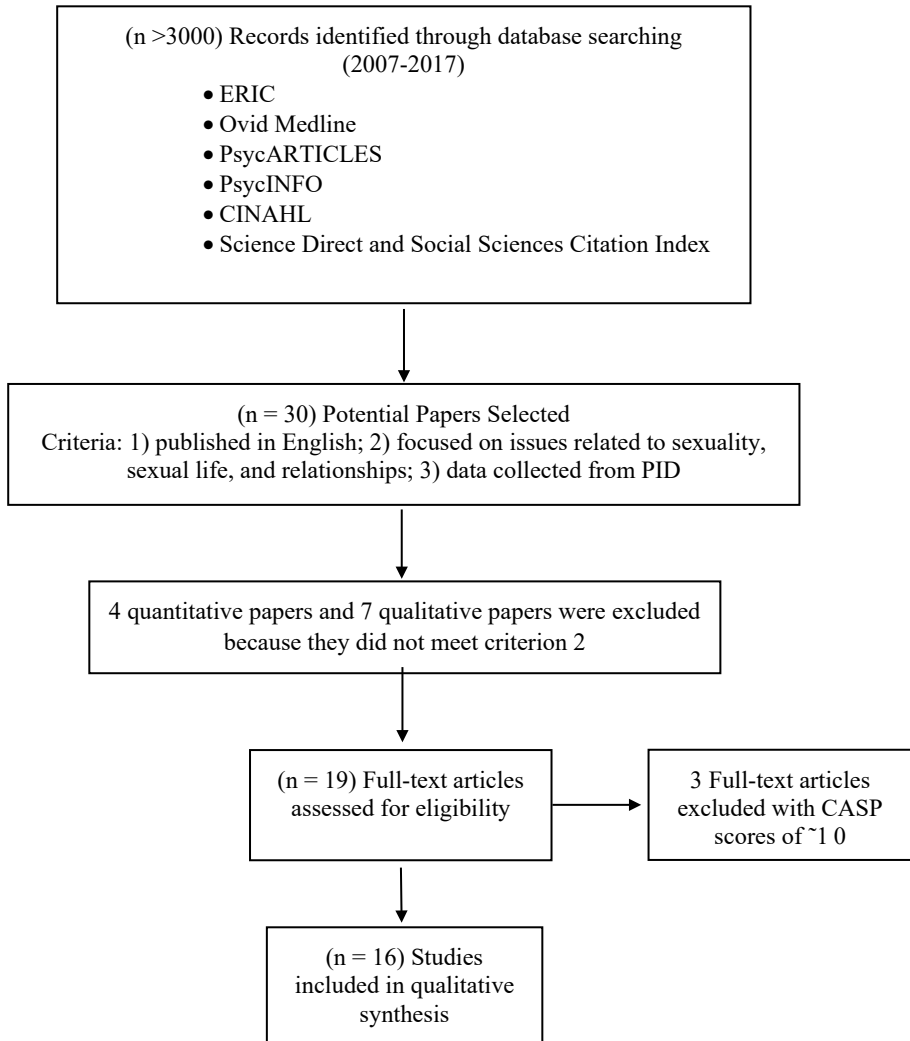


Fig. 1 Flow chart of the search process

the CASP are assigned scores of zero, one, or two, which can be summed to yield total scores of 0–20 points [10]. Zero points are given if little or no information is provided by the article. One point indicates that a moderate amount and quality of information has been identified. Two points indicate that the article fully addresses the information required by the aim of the current study. Accordingly, the CASP score is an indicator of the overall quality of an academic paper.

To filter and identify good quality articles from the giant pool of potential papers, articles with CASP scores of 10 or lower were excluded from the review [1]. This process excluded three additional articles. Finally, 16 papers were selected via consensus among all authors of this paper. The details of these papers are summarized in Table 2.

Table 1 Results of the critical appraisal skills program (CASP)

References	Clear state- ment of aims	Qualitative methodology appropriate	Appropri- ate research design	Appropriate recruitment strategy	Considera- tion of data collection	Consid- eration of research relationships	Ethical issues con- sidered	Rigor- ous data analysis	Findings clearly stated	Value of the research	CASP score
Bernert and Odletree [19]	1	2	2	2	2	2	2	2	2	2	19
Fitzgerald and Withers [15]	2	2	2	1	2	1	1	2	2	2	16
Björnsdóttir et al. [20]	1	2	2	1	1	1	2	2	2	2	16
Bernert [18]	1	2	2	1	2	1	1	2	2	2	16
Healy et al. [24]	2	2	2	2	2	2	1	2	2	2	19
Turner and Crane [6]	2	2	2	1	1	1	1	2	2	2	16
Wilkinson et al. [17]	2	2	2	2	2	1	2	2	2	2	19
Mcclelland et al. [23]	1	2	2	1	1	2	2	1	1	1	14
Turner and Crane [6]	1	2	2	2	2	2	1	1	1	1	15
Schaafsma et al. [14]	2	2	2	2	2	2	2	2	2	2	20
Yacoub and Hall [26]	2	2	2	2	2	2	2	1	1	1	17
Fish [21]	1	2	2	2	2	2	2	1	1	1	16

Table 1 (continued)

References	Clear state- ment of aims	Qualitative methodology appropriate	Appropri- ate research design	Appropriate recruitment strategy	Considera- tion of data collection	Consid- eration of research relationships	Ethical issues con- sidered	Rigor- ous data analysis	Findings clearly stated	Value of the research	CASP score
Frawley and Wilson [25]	1	2	2	2	2	2	2	2	2	1	18
Rushbrooke et al. [1]	1	2	2	2	2	2	2	1	1	1	16
Sullivan et al. [16]	2	2	2	2	2	2	2	2	2	2	20
Yau et al. [13]	1	2	2	2	1	1	1	2	2	2	16

Table 2 Summary of information from the papers selected for the review

References	Title	Aims/research questions	Method	Analysis	Participants	Key findings relevant to the review
Bernert and Odletree [19]	Women with intellectual disabilities talk about their perceptions of sex	To explore sexuality in the lives of women with IDs, the women's understanding of sex in their own terms, and how they assigned meaning to their sexual experiences as expressions of their sexuality	Observation, in-depth interviews	Qualitative—not specified	14 women with intellectual disability	Three themes: 1. very limited sexual experiences given their ages. 2. various conditions or criteria for sex when communicating their meanings of 'sex'. 3. expressed negative perceptions of sex
Fitzgerald and Withers [15]	I don't know what a proper woman means: what women with intellectual disabilities think about sex, sexuality and themselves	To explore how women with intellectual disabilities conceptualize their sexuality or develop a sexual identity	Semi-structured interview	Qualitative—thematic analysis	10 women with intellectual disability	Negative attitude towards sex; think that the participants should not participate in sexual activity
Björnsdóttir et al. [20]	People with intellectual disabilities negotiate autonomy, gender and sexuality	To explore autonomy in the lives of people with intellectual disabilities with the aim of identifying the sociocultural factors that influence the exercise and actualization of autonomy in their daily lives	Interview and observation	Qualitative—thematic analysis	19 individuals with intellectual disabilities for interview, 15 individuals with intellectual disabilities for observation	People with intellectual disabilities are not perceived to have status as autonomous agents and often have limited opportunities to make decisions in everyday life

Table 2 (continued)

References	Title	Aims/research questions	Method	Analysis	Participants	Key findings relevant to the review
Bernert [18]	Sexuality and disability in the lives of women with intellectual disabilities	To explore how intellectual disability influenced the way in which the women experienced their sexuality and how their experiences could inform assistive and supportive services for women with intellectual disabilities	Interview and observation	Qualitative and ethnographic	14 adult women with intellectual disability	Women with intellectual disabilities' adult identities and expectations of sexual autonomy; the experience of limited sexuality because of protective policies and programs
Healy et al. [24]	Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives	To gather information from people with an ID about their knowledge, experiences, and attitudes towards sexuality	Focus group	Qualitative—not specified	32 individuals with intellectual disability	Service users had knowledge of their sexual rights and an acute awareness of the social and cultural impediments to the attainment of those rights
Turner and Crane [6]	Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy	To explore the discourse surrounding sexuality and people with intellectual disability	Interview and observation	Qualitative—thematic analysis	2 women and 3 men with intellectual disability	Sensuality and intimacy are core aspects of social-sexual pleasure for people with intellectual disability

Table 2 (continued)

References	Title	Aims/research questions	Method	Analysis	Participants	Key findings relevant to the review
Wilkinson et al. [17]	As normal as possible': Sexual identity development in people with intellectual disabilities transitioning to adulthood	To investigate the development of sexual identity during transition into adulthood for young people with intellectual disability	Semi structured interviews	Qualitative–interpretative phenomenological analysis	4 individuals with intellectual disability	People with intellectual disability struggled with achieving adult and sexual identities
Mcclelland et al. [23]	Seeking safer sexual spaces: Queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction	To explore the ways in which social and environmental conditions influence vulnerability to adverse sexual health outcomes among people with intellectual disability	Interview and focus groups	Qualitative–not specified	10 individuals with intellectual disability	Participants reported multiple limitations on their autonomy that resulted in having sex in places where they did not feel comfortable and were unlikely to practice safer sex. Attempts by authority figures to protect youth by limiting autonomy may unintentionally lead to negative sexual health outcomes
Turner and Crane [6]	Sexually silenced no more, adults with learning disabilities speak up: A call to action for social work to frame sexual voice as a social justice issue	To explore the personal experiences and perceptions of adults with learning difficulties regarding their social-sexual lives	Interview and observation	Qualitative– thematic analysis	2 women and 3 men with intellectual disability	People with intellectual disability can express their own opinions regarding their social-sexual lives

Table 2 (continued)

References	Title	Aims/research questions	Method	Analysis	Participants	Key findings relevant to the review
Schaafsma et al. [14]	People with intellectual disabilities talk about sexuality: Implications for the development of sex education	To assess the perspectives of people with intellectual disabilities on several sexuality-related topics	Semi-structured interviews	Qualitative—not specified	20 people with intellectual disability	Insufficient sex education provided to people with intellectual disability, and knowledge regarding sex education tends to be superficial and is mainly limited to topics such as safe sex, contraception, and STIs
Yacoub and Hall [26]	The sexual lives of men with mild learning disability: a qualitative study	To explore in detail the sexual lives and behavior of men with mild learning disability and to identify potential unmet needs	Interview	Qualitative—narrative approach	10 men with intellectual disability	Participants generally felt that services had shifted from a paternalistic to a more supportive approach towards their sexual lives and orientations. However, sexual knowledge did not lead to safe sexual practices
Fish [21]	They've said I'm vulnerable with men: Doing sexuality on locked wards	To observe the daily lives of women with intellectual disability and staff with the aim of recommending improvements to such services	Interview and observation	Qualitative and ethnographic	16 women with intellectual disability	Life in a locked ward prevents women with intellectual disability from learning the skills needed to make informed choices about sexual partners

Table 2 (continued)

References	Title	Aims/research questions	Method	Analysis	Participants	Key findings relevant to the review
Frawley and Wilson [25]	Young people with intellectual disability talking about sexuality education and information	To explore the experiences and opinions of people with intellectual disability on the effectiveness of sexuality education	Focus group	Qualitative and grounded theory	14 young men and 11 young women with intellectual disability	Young people with intellectual disability understood the facts and rules but not the “how to” of relationships and sex. However, information access was limited, and they wanted to know and do more
Rushbrooke et al. [1]	The experiences of intimate relationships by people with intellectual disabilities: A qualitative study	To explore the experience of intimate relationships for adults with intellectual disability	Interview	Qualitative– interpretative phenomenological analysis	9 people with intellectual disability	Intimate relationships were desired and important to all participants and fulfilled various needs. However, participants faced a number of challenges related to intimate relationships
Sullivan et al. [16]	Touching people in relationships: a qualitative study of close relationships for people with an intellectual disability	To explore the experiences and perceptions of close and sexual relationships of people with an intellectual disability	Semi-structured interviews	Qualitative– interpretative phenomenological analysis	10 people with intellectual disability	The findings highlight the importance of touch and sexual behaviors in the close relationships of participants. However, negative perceptions were observed to surround sexual behaviors

Table 2 (continued)

References	Title	Aims/research questions	Method	Analysis	Participants	Key findings relevant to the review
Yau et al. [13]	Exploring sexuality and sexual concerns of adult persons with intellectual disability in a cultural context	To explore how people with intellectual disability respond to and perceive sexuality in Chinese society and to identify the sexual issues and concerns among adult persons with intellectual disability, including dating, intimate relationships, and marriage	Semi-structured interviews	Qualitative—not specified	12 people with intellectual disability	People with intellectual disability had been striving for normality and social acceptance and struggled with their own strategies to meet intimacy needs

Analysis

The thematic analysis approach was used to identify the thematic components of the current study. A theme captures an important message from the data in relation to the research question and denotes a certain patterned response or connotation within the reviewed data [11]. A thematic analysis, which minimally organizes and describes data in detail [11], should be considered a foundational method for qualitative analyses, which use extremely diverse, complex, and nuanced methods [12]. Several processes were used to extract the themes of the current study: (1) reading and re-reading to generate initial ideas and codes; (2) generation of a thematic “map” by review of the relevant data, and (3) identification of the kernel and core encapsulation of each theme using the “define and refine” method [11].

Results

For the current review, 16 studies with sample sizes between 4 and 32 PID were selected, yielding a coverage of 215 participants. Five of the studies used semi-structured interviews [12, 14–17], and six used a combination of interviews and observations [6, 18–22]. One described the combined use of interviews and focus groups [23], two reported only the use of focus groups [24, 25], and two interviewed individual participants [1, 26]. The remaining three studies mentioned the use of interviews. Eleven studies (68%) included both genders [6, 13, 14, 16, 17, 20, 22–25, 27], whereas four studies [15, 18, 19, 21] recruited only female participants and one study [26] recruited only male participants. Three studies [16, 17, 27] used an interpretative phenomenological analysis, four used a thematic analysis [6, 15, 20, 22], two used an ethnographic approach [18, 21], one used a narrative approach [26], and one applied a grounded theory [25]. The remaining five studies did not specify the qualitative approach [13, 14, 19, 23, 24].

Sexual Lives of People with Intellectual Disabilities

Three major themes of the sexual lives of PID were identified from the reviewed papers: abstinence, regulation, and autonomy. In the first theme, self- and other-imposed abstinence were identified as subthemes. In the second theme, the sexual expression of PID under regulatory circumstances was the sole category. For the last theme, self-actualizing and struggling were identified as subthemes. Detailed descriptions of each theme identified in the articles are shown in Table 3.

Abstinence

In the general population, people may actively choose to abstain from sexual activity for various reasons, including a wish to wait for the right person with whom to engage sexually, recovery from an illness, or the maintenance of moral or religious principles. In this review, some PID were found to abstain from sexual intercourse or any type of sexual behavior. As noted, two subthemes were identified: (1) self-imposed abstinence and (2) abstinence imposed by others. According to the review, some PID self-imposed

Table 3 Theme by contributing papers

References	Title of the article	Abstinence		Regulating	Autonomy	
		Self-imposed	Restrained by others		Fulfilling	Struggling
Bernert, and Odletree [19]	Women with intellectual disabilities talk about their perceptions of sex	x			x	
Fitzgerald and Withers [15]	'I don't know what a proper woman means': what women with intellectual disabilities think about sex, sexuality and themselves	x	x	x	x	
Björnsdóttir et al. [20]	People with intellectual disabilities negotiate autonomy, gender, and sexuality	x				
Bernert [18]	Sexuality and disability in the lives of women with intellectual disabilities	x				
Healy et al. [24]	Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives		x	x		
Turner and Crane [6]	Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy		x	x	x	
Wilkinson et al. [17]	As normal as possible': Sexual identity development in people with intellectual disabilities transitioning to adulthood		x			x
Mcclelland et al. [23]	Seeking safer sexual spaces: Queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction		x			x
Turner and Crane [6]	Sexually silenced no more, adults with learning disabilities speak up: A call to action for social work to frame sexual voice as a social justice issue		x			x
Schaafsma et al. [14]	People with intellectual disabilities talk about sexuality: Implications for the development of sex education	x			x	
Yacoub and Hall [26]	The sexual lives of men with mild learning disability: a qualitative study		x		x	
Fish [21]	'They've said I'm vulnerable with men': Doing sexuality on locked wards		x			
Frawley and Wilson [25]	Young people with intellectual disability talking about sexuality education and information		x		x	
Rushbrooke et al. [1]	The experiences of intimate relationships by people with intellectual disabilities: A qualitative study		x			x
Sullivan et al. [16]	'Touching people in relationships': a qualitative study of close relationships for people with an intellectual disability		x	x		

Table 3 (continued)

References	Title of the article	Abstinence		Regulating	Autonomy	
		Self-imposed	Restrained by others		Fulfilling	Struggling
Yau et al. [13]	Exploring sexuality and sexual concerns of adult persons with intellectual disability in a cultural context	x	x			

disengagement from any sexual activity, whereas a larger portion of PID reported that they experienced a sexual drive but were forced to regulate or disengage from any sexual expression.

Self-Imposed Abstinence

Under this sub-theme, some PID expressed a perception of sex as undesirable, based on their sexual experiences or perceptions about intercourse. In one study, nine women reported engaging in self-imposed abstinence to avoid sexually transmitted diseases (STD) [18]. In another study, some women with ID also perceived sex as “sickening” [19]. As quoted in the study conducted by Bernert and Odletree: “She hated doing some sexual acts she described as physically painful or making her physically ill.” [19, p. 245]

In addition to STD prevention and the avoidance of undesirable sexual experiences, PID also worried about the consequence of pregnancy. Some PID were constantly reminded by their parents that they were not capable of caring for a baby. In the study by Yau et al. one participant said: “The family suggested to the doctor to sterilize me as I cannot afford to have a baby, and my parents said the baby will be mentally handicapped.” [13, p. 102]

In addition, idealized gender roles appeared to affect the choices of male PID to engage in sexual activity. According to the review, although some male participants expressed interest in friendships with other men and women and most had been in a relationship at some point, few had experienced intimate or sexual relationships. Approximately half of the men wanted to get married and have children, but all stated the importance of being financially independent from the family. Apparently, these men held a fixated and hegemonic perspective of masculinity, in which the ideal woman should be “fit enough” to nurture babies while the ideal man should be the bread-winner [20, 28]. Therefore, the men perceived themselves as incapable of fulfilling this “men’s responsibility” and hence chose to abstain from sexual activity. In a study conducted by Schaafsma et al., a female PID in her 20 s also expressed her concerns regarding caring for a child: “Taking care of a child 24 [hour] a day. I am not sure whether I want that or whether I am able to do that. Because I also have my own problems (...) I already have enough difficulties with myself, what if the child has the same genes as I have?” [14, p. 28], indicating that female participants might also be affected by hegemonic masculinity.

Abstinence as Restrained by Others

Apart from self-imposed abstinence, some PID reported having sexual needs but experiencing restraint by their parents [13]. Some parents even prevented PID from watching any sexual or erotic scenes on television or movies by turning off the media temporarily or asking them to close their eyes [14]. According to Fitzgerald and Withers, a female participant said “My mother said never do it” when asked about her family’s response regarding the participant’s sexual activity with her boyfriend [15, p. 9].

Those restraints were not imposed merely by parents or guardians, but also by service providers [14]. This kind of restraint is not uncommon for service providers to “safeguard” PID from “harm.” However, the imposition of these barrier can have a negative influence on the sexual development of PID and result in sex rejection, regardless of their needs. Under this circumstance, PID may passively choose abstinence. In a study by Fish, a staff member stated that PID could not have physical contact with others privately in their rooms because the whole setting was considered a secure unit, and thus all spaces were classified

as public [21]. In another study, a male participant mentioned the regulation set by the hostel in which he was living: “No, I’m not allowed. I can’t ... they don’t let me ... it’s just the rules in the place. They don’t let anybody stay overnight.” [16, p. 3461].

Intellectual Disability does not weaken a person’s sexual feelings. Most people with mild or moderate ID are capable of expressing sexual desire and making sexual contact [29]. According to the reviewed paper, some PID reported that parents and service providers exercised some governance over their privacy (personal time) and space (e.g., masturbating in their bedrooms). Therefore, although PID expressed desires for sexual and romantic relationships, they were reluctant to talk with their parents or service providers [23]. A 23-year-old male participant expressed his frustration in the study by McClelland and colleagues: “When I was in a group home, I wanted to have sex with another resident, but the group home wouldn’t let us I really wanted to get into sex because I guess I was ready at that point. I was 19. But the group home wouldn’t let us. I was kind of upset and frustrated.” [23, p. 814].

This type of restraint was gender symmetrical (i.e., also applied to female PID). In another study, a female PID reported that although her parents were well aware of her boyfriend, she was reluctant to openly express her emotions about her relationship. She told the interviewer: “I won’t tell her how I’m feeling” and “I’d be embarrassed.” [24, p. 908]

The self-imposition of abstinence is not uncommon in the general population, wherein people may choose not to engage in any sexual activity based on personal decisions. Likewise, PID have the same right to choose sexual abstinence. However, this review revealed some concerns in that area. Although some PID chose abstinence because of negative physical and psychological feelings related to sexual experience, more reported concerns regarding pregnancy and the external regulations imposed on them that made them unable to freely enjoy their sex lives. PID were also found to have inadequate knowledge about sexuality, particularly in the areas of sexual health, safer sex practices, and contraception [30, 31]. Undoubtedly, however, PID is a population with disparities [32]. The power indifference between PID and their families and services providers might affect the process of negotiation. PID might not have adequate power to negotiate with parents and the welfare system regarding the issue of self-determined contraception, regulations on sexual behavior, or the contents of sex education programs, or merely to discuss sexual needs.

Regulation of Sexual Life by Others

The second major theme concerning the sexual lives of PID as generated from the review was “regulation by others”. Although it was clear from the included articles that PID have the same sexual drive as people without disability and that parents and service providers were conscious of the sexual needs of PID, some PID continued to experience regulation of their sexual expression and monitoring by families and agency staff.

People with Intellectual Disabilities can value the meaning of physical contact and its relation to emotional closeness within a relationship [16]. Regardless, PID were often limited to expressing themselves sexually via caressing, holding, hugging, and hair stroking, but not intercourse or other sexual behaviors that require nudity [6]. In one study, a female PID stated: “My mother said it’s alright to have a cuddle and then leave it at that and a kiss but that’s all, not more than that.” [15, p. 9].

Although regulation was imposed, some PID also expressed their satisfaction with this regulated sexual life. One participant said that having her boyfriend’s arms around her

made her feel more secure [16]. A participant in another study reported experiencing some degree of personal and physical intimacy with partner (e.g., holding hands, kissing). A female with ID stated that she and her husband enjoyed having time to “lay together, kiss and cuddle – fondle.” [6].

Sexual behavior is any action that leads to sexual fulfillment, which describes a state of positive affect activated by physical stimulation of the genitalia or mental representations of such stimulation [33]. In other words, sexual behavior can be understood as physical contact together with a psychological phenomenon. A sexual act is not merely a solitary activity, but exists on a continuum ranging from solitary activity (e.g., masturbation) to activity with another person (e.g., sexual intercourse, nonpenetrative sex, oral sex). According to the evidence, PID and their counterparts of people without disabilities have similar sexual expressions and sexual needs. Among PID, the frequency of and reason for engaging in sexual activity also vary [15, 25, 26]. However, the theme of externally imposed regulation indicates that the variety of sexual behaviors exhibited by PID was very limited. In addition, this theme shares a similar pattern with that of abstinence in that the family and service providers have taken substantial actions to intervene in the sexual expression of PID.

Autonomy

A person’s sexual life should be sufficiently open to address all manifestations of oppression. The concept of sexual autonomy is centralized on the idea that each human individual should be respected in terms of the existence of sexuality and the space it requires [34]. This review has identified two subcategories related to autonomy. Regarding the first, self-actualization, PID were not found to differ from the individual without PID and were able to share the pleasure of sexual activity in the absence of any pressure. Regarding the second subtheme, the struggle for self-determination, PID struggled with authority figures for the right and space to engage in sexual activity.

Sexual Life and Self-Actualization

In the included articles, PID stated that sex was pleasurable between two people, especially in a committed relationship. Some PID reported having the autonomy to enjoy a sexual relationship [16]. They also described multifarious sexual experiences, including kissing, having a crush, sexual talk, lovemaking, anal intercourse, oral sex, “playing doctor,” marriage, dating, saying “I love you,” fantasy, masturbation, fellatio, vibrators, and pornography [6]. These various sexual expressions impugn the myth that adult PID lack sexual desire or a mature level of sexual development.

Dailey (1981) described sensuality as physical closeness and an awareness of the reciprocal pleasure that each body can provide [35]. This sensuality is not limited to people without disability per se. In one of the 16 identified studies [6], a male PID excitedly proclaimed that the pleasure experienced from kissing, touching, and orgasms was indeed a part of sensuality for PID. Another female participant in the same study further verified the existence of sensuality by defining masturbation as “get[ting] the release out.” Furthermore, a female participant expressed her positive perception of sex with her boyfriend and described sex as an extension of the overall relationship. She described sexual intercourse as an enjoyable and mutual experience [15]. Another participant in that study stated her

interpretation of sexual life: “I really actually don’t think of it as sex. I think of it as being with a person that you care for.” [15, p. 244].

According to the reviewed papers, PID could identify a relationship as not merely involving sexual intercourse, but also care and love. In the study by Yacoub and Hall, some cohabiting participants expressed their delight in receiving support from an intimate relationship, and one participant stated: “it’s great not just so you can have each other to cuddle after a tough day, but also for ‘comfort’.” [26, p. 9]

Because sexual activity mostly involves intimate interactions with another individual, it can enhance physical satisfaction and social maturity. However, sex can also be a predicament and often a minefield during the process of personal growth. With proper guidance, young people—both those with ID and without disability—can mature and develop into responsible individuals in intimate relationships.

In one study, a young male participant reported having the autonomy to masturbate and stated that: “It is ok to have masturbation because you are a male, you got to do that sort of thing... It is in your hormones, a natural thing. You do it in private places, you never do it in front of anyone... I just masturbate when I watch porn on the computer. My father, he taught me always to respect women. Everyone used to say you shouldn’t be watching pornography but whenever I had my door locked there would be a smart arse comment, my dad would walk in and say ‘you watching porn’ and I would say maybe and he would ask if he could join me. He always taught me about respecting women...” [25, p. 475]. In the same study, a young woman who participated in a stable sexual relationship with support from her mother and counselor reported learning about the use of condoms and safe sex via her mother’s guidance, her own internet research and practice. She also described her ability to negotiate with her boyfriend about sexual needs and plans.

Struggling to have a Sexual Life

Although some PID experience autonomy regarding a sexual life, others continue to struggle for space or approval from parents or service providers regarding sexual activity [1]. Accordingly, parents or family members, as well as the welfare system, are occasionally the “enemy” of the sexual lives of PID. For example, a female participant in one reviewed study managed to exert her sexual voice and live with her boyfriend, although her mother did not like her to talk about marriage [22]. In another study, people with ID reported exerting more efforts in struggling with sexual life autonomy, especially if they were not part of a heterosexual couple. A young male participant identified himself as gay and actively fought the idea that his sexual orientation was not “normal.” By aligning himself with “any other teenager in the world,” he further emphasized his adulthood by shifting the alignment to “any other grown man” and thus asserted that his sexual identity deserved to be acknowledged and respected, despite his negative expectations [17].

The struggle of PID to enjoy sex not only involves the power of autonomy, but also the physical space. For PID who live at home with family well into adulthood or in a hostel, it may be difficult to obtain a private place in which to be affectionate or have sex. According to Couwenhoven [36], sexual activity often moves into the public arena if limits or restrictions are placed on private sexual expression. In one reviewed study, participants mentioned that restrictions placed by family and service providers had led them to explore different places where they had been sexual, including parks, back alleys, behind stores, bathhouses, the street, and other public settings [23]. One 19-year-old gay group home resident spoke of the complications of weather and his fear of getting caught: “The first time

I had sex with someone we went to this park that was nearby and that time I had only half an hour to go on free time so I would have to be back. I hated it... it was in the winter... I was freezing cold and it was like, I was so afraid I was going to get in trouble.” [23, p. 815]

Both cross-sectional and longitudinal individual studies found that sexual well-being is related to life satisfaction [37]. In this review, some PID experienced autonomy regarding their sexual lives and acceptance of their sexuality and demonstrated the capacity to attribute sexual satisfaction to care and love. However, some PID experienced conditional sexual autonomy. Some struggled with the power and control imposed by family and service providers, and others were required to cope with the constraints by using spaces often considered unsafe or inappropriate for sex.

Discussion

Generally speaking, most people without disabilities are self-determined and can freely enjoy a sex life and express their concerns under the spectrum from abstinence to liberty. According to this review, PID experience the same spectrum of sexual expression: some preferred to abstain from sex, whereas others expressed a positive sense of engaging in sexual activity. The three themes synthesized in this review, however, obviously demonstrate that an “unintended invisible hand” created by the PID, their parents, and health professionals influences the rights of PID to engage in sexual behavior.

Sexual well-being can evoke a kaleidoscope of emotions including love, excitement, and tenderness and is a key factor associated with overall mental, physical, and emotional health in humans [38]. Although the family members and service providers of PID acknowledge that sexuality is an essential component of personal identity development, the findings of this review suggest that restrictive or prohibitive approaches remain common at both the individual and institutional levels [39]. This phenomenon is consistent with the findings of previous studies, specifically that PID are often perceived as dependent on others because of a lack of intellectual competence [40] and are even considered permanently incapable of decision-making. Some studies revealed that PID may be considered “eternal children” who are only suitable for participating in monotonous and repetitive tasks [20, 41, 42]. Accordingly, parents might consider it unthinkable to allow a “child” to engage in sexual activity and the fear of such a perceived deviance might evoke a defense mechanism [40]. Health care professionals appeared to experience similar fears. A review study revealed that health care professionals did not proactively discuss sexuality with service users [43]. These professionals’ perceptions of the vulnerability of PID were so robust that they considered it necessary to apply both protection and victim measures to PID [44, 45]. These professional perceptions were also complicated by the fear of possible legal sanction and by ethical and moral conflicts [39, 45]. In summary, families and services providers need to recognize and accept that PID have the same sexual needs and development as people without disability. Nonetheless, both families and service providers encountered tension regarding risk reduction and experienced fear and uncertainty related to the handling of sexuality among PID. These fears and uncertainties have led to the gradual development of the unintended invisible hand and the imposition of regulations on the sexual expression of PID, and possibly even an encroachment of other human rights [27].

The field of rehabilitation has considered the principles of rights, independence, choice, and inclusion of PID since the introduction of “normalization” approximately 40 years ago [27]. In the past decade, increased attention has been directed toward the problems caused

by the disparities experienced by PID and the general population (e.g., employment rights, educational opportunities). Both scholars and governments have accredited the significance of encouraging the active involvement of PID in reducing those disparities and promoting positive health and wellness [46]. Unfortunately, this awareness does not seem to have been applied to the context of sexuality among PID, as indicated in this review. Families and service providers have a dual responsibility to empower and protect PID in terms of matters related to sexuality. Although parents tend to be the most influential and consistent coaches of PID in terms of sexuality, service providers certainly play a role in the communication of appropriate messages. However, the three themes that underlie the sexual lives of PID identified in this review suggest that the trajectory of interference by either the family or/and the welfare system is not an uncommon phenomenon.

Aside from reducing this trajectory of interference, PID could be enabled to achieve self-determination and thus empowerment as suggested by some scholars; in one instance, this could be achieved by increasing sexual education and thus enhancing the sexual literacy of PID [47]. Conversely, a previous review revealed that most sex education programs for PID focused on the transmission of knowledge and not on the development of positive attitudes toward sexuality [48]. In addition, the sex education programs for PID were not found to be effective, despite the commitment of the sex education program developers [49]. Consistent with the findings of this review, this inefficacy might be attributed to the prevalence of parental resistance and the unwillingness of teachers and health care professionals to conduct sex education beyond human physiology [15]. The prejudices of staff and parents were consistently identified as an obstacle to the empowerment of PID to self-determine their sexuality [50]. Undoubtedly, parents and health care professionals are committed to enhancing the rights and quality of life of PID. Nevertheless, the trajectory of intervention in the rights of PID to engage in sexual expression is recognizable, and the disparity in sexual identity among PID becomes systematic and socially constructed, consistent with fixed concepts of hegemonic masculinity and femininity [20, 28]. Together, this disparity in identities and the trajectory of interference by parents and health care professionals form the tripartite “unintended invisible hand” and eventually lead to a *de facto* religious paradigm that comprises autonomy, empowerment, and self-determination but fails to address the original/ultimate function of improving the sexual lives of PID [51].

In the future service development and research might address on various levels (e.g., individual and community). At the individual level, it is essential to examine the perception of sexual self-determination and the factors that currently affect sexuality and sexual expression among PID. At the community level, researchers should use the information gathered from PID to inform parents and professionals with the aim of empowering the sexual self-determination of PIDs via shared understanding and acceptance [8]. Researchers could further foster the sexual self-efficacy of PID by incorporating this information into sexual health promotion initiatives and enabling PID to manage their sexuality in a sensual, satisfying, and safe manner [52]. At the policy development level, researchers could support PID, their parents, and professionals by informing the government of the needs of PID and facilitating policy changes in the perpetuation of systemic barriers. This could be achieved by balancing the crucial components of protection and empowerment of the sexual expression of PID and by cultivating a positive perception of sexuality as expressed by PID [53].

In summary, PID and people without disabilities share a similar wish to enjoy their sex lives and a similar spectrum of sexual expression, and parents and health care professionals are clearly dedicated to nurturing the growth of PID. However, the identification of various themes in this review have led to several recommendations for practice. First, the

involvement of PID should not be ignored. Consultation with PID is required if caregivers and the system are to be informed about their needs. Second, increased support should be provided to caregivers who might need to handle the sexual needs of PID, possibly through training workshops, mutual support groups, and the use of internet and multimedia resources. The domain of concern should cover the concept of normalizing sexuality and relationships among PID and validate the anxiety induced by legal and ethical considerations. The advocacy for the rights of sexuality in the community and to drive changes in policy and culture should be addressed as well. Future research with a specific focus on the experiences of family and services providers in providing support to the sexuality of PID would meaningfully enrich the understanding of the phenomenon of the “unintended visible hand”. An examination of any overarching reason for the fear and reluctance experienced by caregivers when empowering PID with sexual life autonomy is highly important. Furthermore, cultural factors or specific meanings associated with sexuality among PID that would influence the families and service providers in terms of assisting engagement in sexual activity should be identified. Only one of the 16 papers included in this review collected data from an Asian population [13]. Generally, studies have found that Asian cultures are significantly more conservative than non-Asian cultures in terms of sexual attitudes [54, 55]. In addition, Asian culture is generally considered to be collectivistic and thus to emphasize interdependence. Several studies have reported that collectivist groups regularly exert a higher level of control over children, encourage conformity with the family and authorities, and exhibit more restraint during social play and eating [56, 57]. Therefore, additional research on cultural differences in the attitudes of PID, their parents, and service providers toward sexual behavior in Asian communities would be valuable.

Limitations

In this study, the themes were generated to examine the range of emergent issues or themes from data generated in other studies. Further empirical research, in which data are directly collected from PID with the intent to focus on their sexual lives, would be a highly valuable addition to the body of knowledge regarding the sexual needs of PID.

Conclusion

People with Intellectual Disabilities and the general population share the same spectrum of sexuality. However, the promotion of autonomy regarding sexual expression is a challenging task in the PID population. Further research focused specifically on the experiences and challenges of PID, their families and services providers in that area is particularly essential. Further research may also help to guide policymakers who handle the social, legal, and ethical concerns regarding the self-determination of PID to exercise their rights to sexual fulfillment and satisfaction.

Compliance with Ethical Standards

Conflict of interest All Authors declares that they have no conflict of interest.

Ethical Approval This article does not contain any studies with human participants performed by any of the authors.

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Chapter Conclusive Summary

This chapter provides an insight on the sexuality of people with intellectual disabilities. The sexual need of people with intellectual disabilities is acknowledged. The potential barriers that would impact the autonomy of sexuality of people with intellectual disabilities is also discussed. In addition, future research on cultural influence on the attitudes of people with intellectual disabilities, their parents, and service providers toward sexual behaviour is recommended.

Man is a social animal. Society is an environment that individual is surrounded and encompassed by culture, as a societal force. Society liberates and limits the activities of men, and they are expected to conform to the norms, which is a necessary condition of every human being and fulfilment of life. As human being cannot live without association, the next chapter will review how the general population perceive the sexuality of people with intellectual disabilities, and will explore any potential factors that would influence that perception.

Chapter Three

Insight: the perspective of public, parents, and health care professions on sexuality of people with intellectual disabilities

Chapter Overview

Chapter 3 contains the second literature review to discuss the knowledge gaps for this doctoral study. By reviewing the 11 quantitative papers, the review first identified the opinion on sexuality of people with intellectual disabilities from public. It further compared the opinion in between public and two significant parties of people with intellectual disabilities: parents and health care professions. Prior to the end of the chapter, the direction for future study was presented.

Chapter structure

This section is based on a publication (Publication 2) in the *Sexuality and Disability*. In the next page, as in the format of the journal article, the published paper will be presented. Later, a conclusive summary would put the works of the two literature reviews in a nutshell.

Citation of the paper: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2020). Public Opinion on the Sexuality of People with Intellectual Disabilities: A Review of the Literature. *Sexuality and Disability*, 39(2), 395-419. doi:10.1007/s11195-020-09674-9



Public Opinion on the Sexuality of People with Intellectual Disabilities: A Review of the Literature

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Accepted: 23 December 2020

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Abstract

People with intellectual disabilities (PID) experience the same range of sexual thoughts, feelings, desires, and activities as anyone else. However, the public's view, especially about stereotypes, is noticeable to have an impact on sexuality and people with disabilities, thereby influencing the population which includes the families of PID, healthcare professionals, and policymakers. This review aims to analyze the opinions of public, family of PID or care staff on the sexuality of PID and the methodology applied. Eleven quantitative peer-reviewed papers were identified. Participants' attitude could be evaluated as a binary classification of either "Restrictive" or "Acceptance" in four aspects. Demographic background and the conditions of the PID were found to have an influence on people's attitudes. People acknowledge that PID are not asexual but generally the public holds a more accepting attitude towards the sexuality of PID when compare with family of PID or care staff. Further research on this attitude gap is particularly essential, as this will contribute valuable information and provide insight to policymakers on handling the social, legal and ethical concerns about the sexuality of PID.

Keywords Intellectual disabilities · Public · Sexuality · Sexual expression · Culture · Hong Kong

Introduction

Sexual activities and desires are natural aspects of being human. For people with intellectual disabilities (PID), the information available on sexuality is usually limited to abuse or pregnancy prevention, rather than through the lens of the universal need for affection and intimacy as ordinary people [1–3]. On one hand, sexual health education for PID is perceived as a sensitive subject or even a taboo, in which caregivers prohibit the discussion implicitly. On the other, healthcare staff often manifest anxiety and unwillingness to

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implement programs related to sexual education, or empowering PID to achieve self-determined sexuality [3–5].

Furthermore, meaning is created as a result of interactions between people, and meaning allows people to produce some of the facts to form the sensory world [6]. Humans are by nature social beings and thus most individuals tend to conform to society and social norms to maintain social connections. Society is something that precedes the individual. In order to better understand why the sexuality of PID is a sensitive subject, it is essential to examine the social context that has maintained it [7, 8]. The influence of the public's views on sexuality and people with intellectual disabilities is noticeable, especially their stereotyping and negative attitudes. This influence covers the population including the families of PID, healthcare professionals, and policymakers. According to Scior, public knowledge about intellectual disabilities and the causation is a particularly under-researched area, with an absence of well-designed evaluation to reduce misconceptions about sexuality and PID, and thus tackle stereotypes and stigma [9].

To enable an in-depth understanding of the social context in sexuality, and to assist the families of PID, healthcare professionals, policymakers and researchers to recognize existing limitations in research and service models, and to align their support with the sexual needs of PID, this literature review aims (1) to review the public opinions on the sexuality of PID reported in the peer-reviewed literature, and (2) to identify limitation(s) in the methodology employed for collecting the public opinions on the sexuality of PID.

Methods

Search Strategy Used in This Study

A literature search was conducted in June 2019. Historically, the terms “mental retardation” and “mental handicap” were commonly used for the population of PID [10]. To ensure that most relevant papers would not be excluded from the search results, the following keywords were selected to meet the aims of the study: intellectual disability, mental retardation, mental handicap, learning disability, sexuality, sexual behavior, sex education, sexual relationship, sexual health, and attitude. All articles were selected from peer-reviewed journals using the following online databases: ERIC, Ovid Medline, PsycARTICLES, PsycINFO, CINAHL, Science Direct and Social Sciences Citation Index (Fig. 1).

The search covered the period from 2000 to 2019 and identified over 3000 of potential papers that might match the aims of the review. The selection of papers was based on the PRISMA flow chart [11] and was carried out by repeated reading and analyzing of potential paragraphs and data. The search results were then filtered to yield a final list of articles for review. The review process used the following inclusion criteria: (1) publication in English; (2) focus on issues covering public opinion on the sexuality and sexual life of PID. This filter strategy initially identified 12 potential papers, which all were quantitative studies.

Data Quality Assessment

To determine a minimum quality threshold for the 12 potential papers selected for this review, the Effective Public Health Practice Project (EPHPP) quality assessment tool for quantitative studies was selected [12] as a secondary level of analysis on data quality.

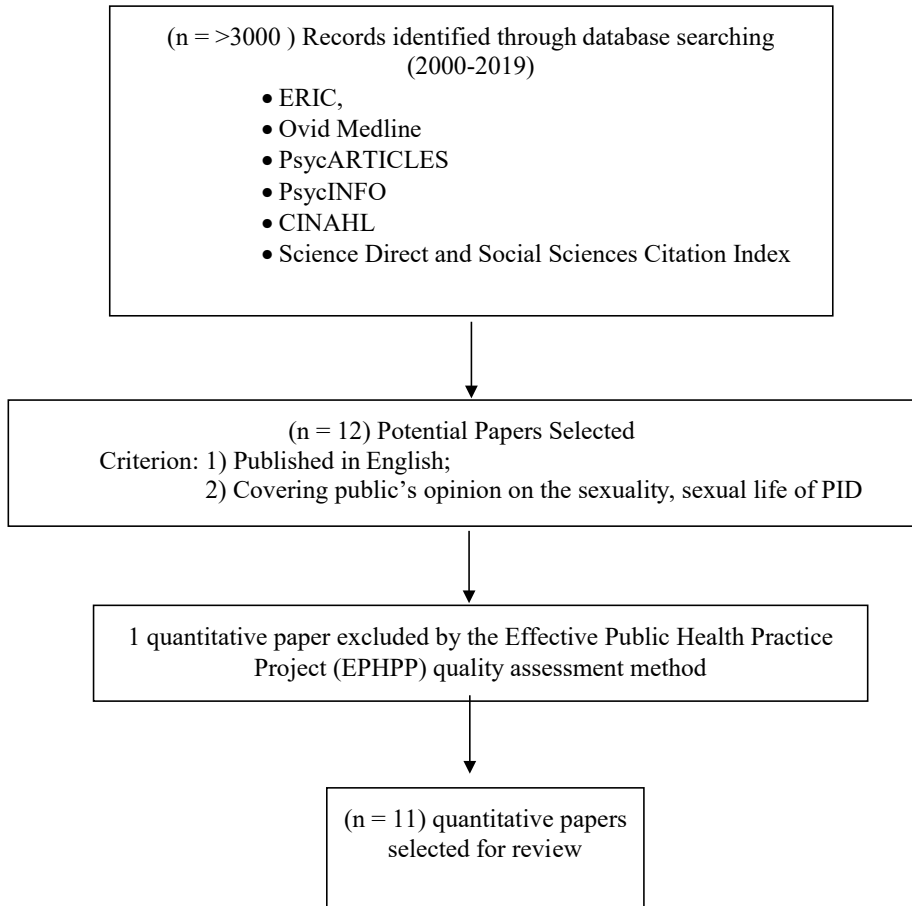


Fig. 1 Search process flow chart

The EPHPP has been judged suitable to be used in systematic reviews of effectiveness. It consists of six assessment criteria: (1) selection bias, (2) confounders, (3) blinding, (4) data collection methods, (5) withdrawals and dropouts, and (6) analyses. The six criteria were each rated as “strong,” “moderate,” or “weak” depending on the characteristics of each criterion reported in the study. Each study received a global rating of “strong,” “moderate,” or “weak” quality by totaling the rating given in the tool. For a study to be rated as “strong,” four of the six quality assessment criteria had to receive rating at “strong” and without any weak ratings. A rating of “moderate” was given if less than four criteria received “strong” and one criterion was rated as “weak”. A rating of “weak” was given if two or more criteria rated “weak”. Only papers with the global rating of “strong” or “moderate” were selected for the review. Finally, 11 papers were selected for review (Table 1).

Analysis

To reveal the connection between various contributing factors from the entire collection of papers reviewed, it is essential to provide a clear framework to assist readers to develop

Table 1 Results of the Effective Public Health Practice Project (EPHPP)

Ref #	1st Author	Title	Selection bias	Confounders	Blinding	Data collection method	Withdrawal and drop-outs	Analyses	Global rating
15	Chou (2016)	Comparison of attitudes to the sexual health of men and women with intellectual disability among parents, professionals, and university students	S	M	S	S	M	S	S
16	Marco (2013)	Attitudes towards the sexuality of men with intellectual disability: the effect of social dominance orientation	M	M	S	S	M	S	M
17	Cuskelly (2004)	Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample	S	M	S	S	M	S	S
18	Cuskelly (2007)	Attitudes to Sexuality Questionnaire (individuals with an intellectual disability): scale development and community norms	S	M	S	S	M	S	S
19	Esterle (2008)	Judging the acceptability of sexual intercourse among people with learning disabilities: French laypeople's viewpoint	S	S	S	S	M	S	S
20	Morales (2011)	Acceptability of sexual relationships among people with learning disabilities: family and professional caregivers' views in Mexico	M	S	S	S	M	S	S
21	Franco (2012)	Attitudes towards affectivity and sexuality of people with intellectual disability	M	S	S	S	M	M	M
22	McConkey (2013)	Irish attitudes to sexual relationships and people with intellectual disability	S	S	S	S	M	S	S
23	Sankhla (2015)	British attitudes towards sexuality in men and women with intellectual disabilities: a comparison between White Westerners and South Asians	S	S	S	S	M	S	S

Table 1 (continued)

Ref #	1st Author	Title	Selection bias	Confounders	Blinding	Data collection method	Withdrawal and drop-outs	Analyses	Global rating
24	Ditchman (2017)	The impact of culture on attitudes toward the sexuality of people with intellectual disabilities	S	S	S	S	S	S	S
25	Tamas (2019)	Professionals, parents and the general public: attitudes towards the sexuality of persons with intellectual disability	M	S	S	S	M	S	S

S strong, *M* moderate

a systematic understanding on the review [13]. The main purpose of this review was to obtain a brief qualitative description of the empirical results. Considering the disparity among the reviewed articles with regard to approaches, sampling, methodology (research design), etc., the authors did not draw conclusions about the causal relations between the variables. Instead, to achieve the aims of reviewing the public opinions on sexuality of PID, the first author examined the selected articles and subsequently with consensus made by all authors, the results then presented in a schematic way [14]. Four categories were subsequently identified and confirmed by all the authors, which are: Sexual Rights (SR), Parenting (Pt), Non-reproductive Behavior (NRB), and Self-control (SC). The first category, Sexual Rights (SR), referred to participants' attitude toward the needs of PID for intimate/sexual relationships, sexual interest, intercourse, and marriage [15]. The second category, Parenting (Pt), related to PID's autonomy or "being permitted" to have children within marriage [15]. For the third and fourth category, Non-reproductive Behavior (NRB) referred to gay/lesbian relationships and masturbation [16] while Self-control (SR) referred to the capacity of PID to control their sexual desires and feelings [15].

Results

Overall Findings

The papers reviewed were not published in a sequential or concurrent pattern: three papers were published between 2000 and 2010 [17–19], while the remaining were published in the years between 2011 and 2019. A summary of the methodology of the reviewed papers is presented in Table 2. For the current review, 11 studies with sample sizes ranging from 122 to 1039 were found. Except the study conducted by McConkey and Leavey [20] which employed a randomized technique, all the participants of the other studies were recruited by convenience sampling. Six of the studies recruited participants from the general population [17–22], while the others recruited from universities or were the parents of children without disabilities [15, 16, 23–25]. Some studies recruited helping professionals or support staff and parents of PID as a comparison group [15, 17, 22, 23] and one study used a student sample with healthcare background for comparison [24]. For the locality of the studies, only one study was conducted in a Chinese-speaking country [15] but two other studies were found to have participants with Asian background [21, 22]. Two studies conducted by Cuskelly took place in Australia [17, 18] while the data of the other studies were collected from European countries [19, 20, 22, 24] and North America [23, 25], respectively. Regarding the tool for collecting opinions on the sexuality of PID, the Attitudes to Sexuality Questionnaire—Individual with an Intellectual Disability (ASQ-ID) developed by Cuskelly was the most frequently used [15–18, 21, 22, 25]. Two other studies used a scale developed by the authors [20, 24] and two studies employed a vignette to ask for opinions from participants [19, 23].

The attitude of the participants of the studies reviewed towards the four categories (Sexual Rights, Parenting, Non-reproductive Behavior, and Self-control) were evaluated according to a binary classification of either "Restrictive" or "Acceptance." In brief, "restrictive" refers to an attitude with the tendency to deny sexual expression and constrain access to sexual information. On the contrary, "acceptance" refers to a paradigm to view sexual expression of PID as morally valid and as a natural human being. The articles reviewed revealed some crucial factors that correlated to this dichotomous attitude towards PID

Table 2 Summary of the methodology of the papers reviewed

Ref.	1st Author	Title	Aims of the research	Country	Sample (n)	Sample for comparison (n)	Tools for evaluation	Major findings
22	McConkey (2013)	Irish attitudes to sexual relationships and people with intellectual disability	To monitor changes from 2001 to 2011 in Irish attitudes towards the right to sexual fulfilment of persons with disabilities and with mental health difficulties, and for them to have children if they wish To identify those persons who are most likely to disagree with the right to sexual fulfilment and to have children To identify the main reasons given for these disagreements	Dublin, Ireland	General population (1039)	N/A	A structured questionnaire developed by author	Concerns were around a person's capacity to make a decision and the potential being abused when talked about sexual relationships PID having children centred mainly on the well-being of the child

Table 2 (continued)

Ref.	1st Author	Title	Aims of the research	Country	Sample (n)	Sample for comparison (n)	Tools for evaluation	Major findings
25	Tamas (2019)	Professionals, parents and the general public: attitudes towards the sexuality of persons with intellectual disability	To investigate attitudes of professionals working with persons with ID, as well as parents of persons with ID and the general population towards the sexuality of persons with ID as well as the influences on the development of their sexual identity	Serbia	General population (165)	Parents of persons with ID; professionals working for PID (137)	The attitudes to Sexuality Questionnaire—individuals with an intellectual disability—ASQ-ID	Attitudes of professionals on the sexuality of persons with ID mainly show conservative viewpoints Parents feel unprepared to educate their children on the subject of sexuality More liberal attitudes in members of the general population
18	Cuskelly (2007)	Attitudes to Sexuality Questionnaire (individuals with an intellectual disability): scale development and community norms	To establish the factor structure of the scale To undertake a separate examination of attitudes to the sexual expression of men and women with an ID To compare the attitudes to the sexual expression of individuals with an ID with attitudes to the sexual expression of typically developing adults	Australia	General population (251)	N/A	The attitudes to Sexuality Questionnaire—individuals with an intellectual disability—ASQ-ID	Generally positive towards the sexual right of PID, but found that the higher the age, the less positive attitude Views about parenting by people with an ID were more cautious than for other aspects of sexuality

Table 2 (continued)

Ref.	1st Author	Title	Aims of the research	Country	Sample (n)	Sample for comparison (n)	Tools for evaluation	Major findings
17	Cuskelly (2004)	Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample	To examine the attitudes about the sexual expression of individuals with an intellectual disability, held by parents and support staff of PID and by the general community	Australia	Community member + university students (63)	Parent of PID (43) Support staff (62)	A structured questionnaire developed by authors	Older participants held less liberal attitudes Parent and staff were less positive about parenthood

Table 2 (continued)

Ref.	1st Author	Title	Aims of the research	Country	Sample (n)	Sample for comparison (n)	Tools for evaluation	Major findings
21	Franco (2012)	Attitudes towards affectivity and sexuality of people with intellectual disability	To evaluate whether the sex of the respondent or the frequency of their contact with people with intellectual disability influences their attitude towards their sexuality and affection To assess how the academic skills and knowledge acquired over medical and psychology courses influence attitudes towards sexuality and affectivity of the individual with intellectual disability To evaluate whether students who choose an academic course of medicine and psychology already have a more positive attitude in what concerns affectivity and sexuality of young people with intellectual disabilities	Covilha Portugal	Architecture student (79)	Medicine student (266) Psychology student (109)	Scales developed by Martins, A. and Ramos, M.L.P	The students of psychology were those with a more positive attitude towards sexuality and affectivity of the PID, while the least positive was taken by the architecture students

Table 2 (continued)

Ref.	1st Author	Title	Aims of the research	Country	Sample (n)	Sample for comparison (n)	Tools for evaluation	Major findings
20	Morales (2011)	Acceptability of sexual relationships among people with learning disabilities: family and professional caregivers' views in Mexico	To compare lay people's attitudes with the attitudes of family caregivers of PID and professional caregivers of PID	Northern Mexico	Parent of children without learning disability (120)	Family caregivers (75) and professional caregivers (75)	Asking participants to read different vignettes: level of autonomy, use of contraceptive technique	The use of contraception was by far the major determinant of acceptability
16	Marco (2013)	Attitudes towards the sexuality of men with intellectual disability: the effect of social dominance orientation	To explore the attitudes of university students towards the sexuality of men with ID	Italy	University students (122)	N/A	The attitudes to Sexuality Questionnaire—individuals with an intellectual disability—ASQ-ID	Less acceptance and the comprehension of sexual needs of PID, if participants were found to have higher prejudice attitude
23	Sankhla (2015)	British attitudes towards sexuality in men and women with intellectual disabilities: a comparison between White Westerners and South Asians	To evaluate the difference between South Asians and White Westerners in attitude towards sexuality of PID	United Kingdom	General population: White Western (184)	General population: South Asian (147)	Attitudes towards sexuality in the general population (ASQ-GP) The attitudes to Sexuality Questionnaire—individuals with an intellectual disability—ASQ-ID	South Asian were more conservative in their attitudes towards sexual right of PID, parenting right of PID, Self-control of sexuality of PID then White Westerners

Table 2 (continued)

Ref.	1st Author	Title	Aims of the research	Country	Sample (n)	Sample for comparison (n)	Tools for evaluation	Major findings
15	Chou (2016)	Comparison of attitudes to the sexual health of men and women with intellectual disability among parents, professionals, and university students	To explore the difference in attitude to sexuality of PID between parents, professionals and general public	Taiwan	University students (645)	Parents (130) Professionals (173)	The attitudes to Sexuality Questionnaire—individuals with an intellectual disability—ASQ-ID	University students hold more positive attitude than the other two groups Cultural factor emphasized favoring son over daughters in patriarchal society and religion factor were found to have influence on participants' response
19	Esterle (2008)	Judging the acceptability of sexual intercourse among people with learning disabilities: French laypeople's viewpoint	To examine the acceptability judgment on sexuality of PID	Southern France	Community members (500)	N/A	Asking participants to read different vignettes: level of autonomy, use of contraceptive technique	Younger participants held positive attitudes then the older population Age of PID and their ability to take care of a child was a concern

Table 2 (continued)

Ref.	1st Author	Title	Aims of the research	Country	Sample (n)	Sample for comparison (n)	Tools for evaluation	Major findings
24	Ditchman (2017)	The impact of culture on attitudes toward the sexuality of people with intellectual disabilities	To investigate the attitudes toward the sexuality of PID	Midwest United States	Participant from university (227)	N/A	Attitudes towards Sexuality Questionnaire (ASQ-ID)	Participants with horizontal collectivism were associated with more positive attitudes, and vertical individualism was associated with more negative attitudes

sexuality. These factors could be divided into two major groups: (1) demographic background of the participants, and (2) conditions of PID. For the demographic background, age, gender, ethnics background of the participants and personal attitude were found to be the factors influencing the participants' attitude towards the sexuality of PID. Regarding the conditions of PID, gender, cognitive capacity of PID, the level of support from others and the use of contraception were found to be correlated to participants' attitude as well. Among the 11 reviewed papers, six papers used the Attitudes to Sexuality Questionnaire—Individual with an Intellectual Disability (ASQ-ID) [15, 16, 18, 21, 22, 25] and another paper could be regarded as the pilot study for the ASQ-ID [17]. For those papers, the public was found to consistently hold a more accepting attitude towards the sexuality of PID, when compared with the groups of parents of PID or service providers. The analysis of the four categories and factors is shown in Table 3.

Factors Related to the Demographic Background of the Participants

Age and Gender of Participants

Among the 11 reviewed papers as presented in Table 3, three of them indicated that participants' age could have an effect on the attitude towards the sexuality of PID [17–19]. All these papers reported that the older the participants, the more restrictive their attitude towards the Sexual Rights of PID. On the other hand, five of the studies discussed the different attitude between gender [17, 18, 21, 24, 25] but only two of them found a significant difference on the participants' attitude towards the sexuality of PID, particular in the category of Sexual Right [24, 25].

Background of the Participants

Four studies recruited parents or caregivers of PID as participants [15, 17, 22, 23]. Two of them reported that parents of PID held a restrictive attitude towards the sexual rights of PID [15, 22]. In the study conducted by Chou, et al., the parents of PID were reported to show less accepting attitude in regard to three categories: Parenting, Non-reproductive Behavior and Self-control [15]. In the study conducted by Cuskelly, the parent group was also found to hold restrictive attitudes towards the sexual expression of adults with intellectual disabilities [17]. However, the participant's age appears to be a variable influencing this result. When examining the data carefully, the parent group in this study was the oldest when compared with another sample. Apart from parents being the most influential and consistent coaches of PID, service providers certainly play a role in communicating appropriate messages related to sexuality [5]. Among the papers reviewed, four studies recruited professional staff or supported staff as participants [15, 17, 18, 22] and the results varied: studies carried out by Tamas and Cuskelly found that professional staff were holding a more restrictive attitude in the categories of Sexual Rights [22] and Parenting [17, 18], respectively. The study done by Chou and colleague also found that professional staff were shown to have a restrictive attitude in the aspects of Sexual Right, Parenting, and Self-control [15]. In the study [23, 24], on the contrary, professional caregivers were reported to hold a more accepting attitude about the sexual rights of PID.

Public opinions on the sexuality of PID, indeed, were the focus of this review paper. Except the paper conducted by Esterle and Ditchman [19, 25], most reviewed papers compared the attitudes towards the sexuality of PID between the general public and

Table 3 Factors influencing participants' conservative/liberal attitude towards sexuality of PID

Ref.	1st Author	Factor related to demographic data							Factor related to PID				
		Higher in age	Female	Parent	Profession-als/staff/students with health care study background	Public	With Asian background	Stronger discriminating attitude	PID is male	PID is older	PID with more support	PID is with moderate or severe ID	PID using contraceptive
17	Cuskelly (2004)	SR Pt		R	R	A						R	
18	Cuskelly (2007)	SR Pt			R	A			R R				
16	Marco (2013)	SR Pt NRB				R A		R					
23	Sankhla (2015)	SR Pt NRB SC					R R R R						
15	Chou (2016)	SR Pt NRB SC		R R R R	R R A R	A A A A							
24	Ditchman (2017)	SR Pt	A					R R					

Table 3 (continued)

Ref.	1st Author	Factor related to demographic data							Factor related to PID				
		Higher in age	Female	Parent	Profession-als/staff/students with health care study background	Public	With Asian background	Stronger discrimi-nating attitude	PID is male	PID is older	PID with more sup-port	PID is with moderate or severe ID	PID using contra-ceptive
25	Tamas (2019)	SR Pt NRB SC		R	R	A			R R R				
19	Esterle (2008)	SR	R								A	R	A
20	Morales (2011)	SR			A								A
21	Franco (2012)	SR		A	A	R							
22	McConkey (2013)	Pt				R							

SR sexual rights, Pt parenting, NRB non-reproductive behavior, SC self-control, R restrictive, A acceptance

other populations, but no universal opinion was found. In the area about Sexual Rights of PID, five studies compared the opinions between the public and other populations [15–18, 22]. Three of the studies revealed that the public held a more accepting attitude in this area [15, 18, 22]. Regarding the category of Parenting, five studies reported the opinions of the public and other populations, in which an inconclusive pattern was found. Three studies reported that the public held a more accepting attitude to accept PID having children within marriage [15, 18, 22], while the others [16, 20] held an opposite stand. In the area of Non-reproductive Behavior, for example, gay/lesbian relationships and masturbation, a comparatively more consistent finding was revealed. Three of the studies showed a permissive attitude from the public on sexual preference (/expression) among PID [15, 16, 22].

Conservative attitudes regarding sexuality, for example, sexual intercourse is accepted only within the context of marriage, disapproval of masturbation, generally, are comparatively more commonly found in Asian cultures [26, 27]. Among the reviewed papers, three studies recruited participants with Asian background [15, 18, 21] but only one of them compared the attitude of Asians to the opinions from another ethnicity [21]. In the study [21], a group of South Asians living in the United Kingdom were recruited. Under the four themes suggested in the review of the sexuality of PID, the Asian group reported having a restrictive attitude when compared with Caucasians.

The formation of personal attitudes is complicated but one of the formation pathways is through categorizing people in society into different groups. Social human beings are easily affected by this continuous categorization between groups and are encouraged to develop social stratification and competition into dominant and inferior groups implicitly [28]. As personal attitudes of the participants was also found as a factor influencing their attitude towards the sexuality of PID. In short, the more restrictive the view of PID's sexuality, the greater chance of discriminative attitude could be observed. The in-group and out-group competition could be manifested by stigmatization and discrimination, which is correlated with the prejudice towards disabled people [29]. Studies [16, 25] reported the higher discriminating attitude of participants, the more restrictive attitude towards the Sexual Rights of PID and less acceptance to Parenting in Study.

Factors Related to the Conditions of People with Intellectual Disabilities

As shown in Table 3, Gender, cognitive capacity of PID, and the support received from others or the use of contraceptive methods by PID were found to be influential to participants' attitude. In study [18, 22], participants reported a concern for Sexual Rights, Parenting and Self-control of males with intellectual disabilities. Another two studies reported that cognitive functioning as a determinant of participants' attitude. If PID have moderate or severe intellectual impairment, participants reported to have a less accepting attitudes in the areas of Parenting [17] and Sexual Rights [19], respectively.

Two more factors, support from others and capacity to use contraceptive methods, were found to have a correlation on having a comparatively high acceptance level of the participants of the studies reviewed. If participants perceived PID as having more support from others, they appeared to hold a more accepting attitude towards the Sexual Rights of PID [19]. In addition, if the participants perceived PID are capable to use contraceptive methods, they tended to have higher level of acceptance towards the Sexual Rights of PID [19, 23].

Discussion

The opinions of the general public are important in influencing the likely realization of policies and services, particularly in broadening the idea of social inclusion of people with intellectual disabilities, ranging from the scope of vocational and community living skills to the consideration of companionship and sharing love. The present paper provides an appraisal of articles published in English between 2000 and mid-2019. The review achieves the aim of reviewing public opinions on the sexuality of PID with identification of factors influencing people's judgment of sexual rights, parenting, non-reproductive behavior and self-control of PID. In general, participants' opinions in the reviewed papers indicated that they acknowledged PID as not "asexual", and the public generally held an accepting attitude towards the sexuality of PID. The demographic variables and the characteristics of PID, for instance, gender of PID and their capacity to be a parent, however, are found to be the influential factors affecting people's attitude towards the sexuality of PID.

Demographic Variables: Age, Gender and Background of People Participated in the Studies Reviewed

The age and gender of participants were found to be crucial factors influencing the attitude towards sexuality issues of PID. First, older participants exhibited a trend of holding a more restrictive attitude towards the sexuality of PID [17–19]. Second, the present study revealed that males tended to hold a comparatively restrictive attitude towards the Sexual Rights and Parenting issues of PID [22, 24].

Stigma maybe a possible factor correlating to the aforementioned findings. Stigma is defined as the public's attitude toward a person who possesses an attribute that fails to meet societal expectations and who is consequently perceived as "deeply discredited within a particular social interaction" [30]. Stigma has been cited as one of the potential barriers to the delivery of adequate services to people with learning disabilities [31], resulting in receiving poorer treatment, rejection, and devalued roles within society [32]. Evidence suggests that older people and male participants tended to hold a negative attitude towards PID when compared to the younger generation and female participants. In previous studies, older people were found to hold attitudes that reflect greater social distance to PID [33] and holding less accepting attitudes towards the sexuality of PID as well [34, 35]. In the present review, male participants and older people who were holding a stronger discriminating attitude were also found to have less accepting attitudes toward the Sexual Rights and Parenting issues of PID [16, 25], which is consistent with the findings suggested by Scior [9].

A stigmatizing attitude can be exhibited in another way. This attitude is communally generated from shared values, prejudices and taboos and is woven at the very deepest level of the fabric in a society, and manifested by a pattern of subconscious behaviors of society's members. Stigma is also the servant of taboo that is embedded in the public and individual consciousness in that a society's members protect themselves from harm or the destructive influence of those who are different [36]. In the present review, South Asian participants were reported to hold a restrictive attitude in four abovementioned themes towards the sexuality of PID when compared with Caucasian [15]. Traditional Asian norm enmeshed with stigma which in turn impacting people with Asian background were more likely to opine that people with ID should be sheltered and not empowered [37, 38]. Moreover, sex is perceived as a taboo, and thus sexuality in Asian countries might not

correspond with the knowledge, beliefs, and behaviors of people in Western societies [26]. Furthermore, it is not uncommon to observe in media the use of metaphors and euphemistic figurative language to reflect the discussion of sex, rather than mentioning “sex” explicitly. Besides, Chinese parents prefer to be silent about their own sexual lives, as well as topics related to sex. They also tend to exhibit more control over the sexual lives of their adult children with intellectual disabilities [15, 21].

To reduce stigma and discrimination, there is no doubt to support public policies which stress equal rights and social inclusion for people with special needs. In addition, the promotion of inclusive education and vocational training may help to enhance the social inclusion of PID by enhancing closer social contact between PID and the general public, starting at the stage of schooling. According to different research, public education focusing on fact-telling of PID is the strongest way to address public stigma change. Further, the frequency, quantity and quality of social contact have also been shown to promote positive attitudes to and social integration of PID [39, 40].

Demographic Variables: with the Role as Parents and Healthcare Staff

In addition to participants’ age and gender and ethnics background, the role of participant is another important variable that impact sexuality of PID, in particular the parent of PID and health care staff. Parents, to a very large extent, tend to be the most influential and consistent coaches of PID in the area of sexuality. Health care staff certainly play another critical role in the communication of appropriate messages related to sexuality. As mentioned at the beginning of this paper, human interaction allows individuals to form perceptions from their sensory world. However, it seems that there is an unspoken and invisible gap between these two care giving parties and the general population in terms of social interaction with PID and sexuality of PID. The current review suggested that family members and healthcare staff of PID tend to hold a restrictive attitude to the sexuality of PID, when compared with the opinions of the general public. This kind of “attitude gap” has been maintained across time, from the first decade of the new millennium to the present year. This kind of “unintended invisible hand” is believed to influence the rights of PID to engage in sexual behavior [5]. Perceptions of the functional level of intellectual ability by parents and staff may influence the methods of management among carers and may lead to an inconsistent approach to care giving [41]. According to research, PID are often perceived as dependent on others because of a lack of intellectual competence and are even considered permanently incapable of decision-making [42]. The concept of “eternal children” also strengthens the practice that PID are only capable of participating in monotonous and repetitive tasks [43]. On one hand, parents might consider it is unacceptable and “unthinkable” to allow a “child” to engage in sexual activity and that the anxiety of such a perceived deviance might evoke a defense mechanism [44]. On the other hand, healthcare professionals appear to experience a similar anxiety which is complicated by the fear of possible legal sanction and ethical and moral conflicts [45, 46].

Characteristics of People with Intellectual Disabilities: Gender of PID

The current review identified an unexpected finding that the participants generally held a more accepting attitude towards the sexuality of females with ID. To explain this, one of the reasons appeared to be the prevalent beliefs of lower males’ self-control of their sexual drive. Research from multiple sources of evidence suggested that males’ sexual drive

tended to be more intense and uncompromising than that of females [47, 48]. The respondents of the study by Gilmore and Chambers indicated that they mostly perceived men with ID as having less self-control over their sexual behavior than women [49]. Another possible factor relating to this different view on gender could be related to the physical differences between men and women. Men on average have a larger physical stature than women; thus, if sexual behaviors, for example, masturbation, sexual intercourse, or sexual stimulation, are being displayed at an inappropriate time and setting, a man is believed to be more challenging to manage [50].

Characteristics of People with Intellectual Disabilities: Parenting Capacity of PID

Although the public shows the tendency of having a more accepting attitude to the sexuality of PID [15–18, 22], parenting was found to be a comparatively restrictive area with complications and conditions [16, 20]. The participants of two reviewed papers who shed light on the more restrictive attitude toward people with moderate and severe ID in regard to Sexual Rights [17, 19], but contradict with a more accepting view if contraceptive methods were used [19, 23], or if the PID received more support from others [19]. Sexual well-being, indeed, is not just about sexual intercourse but consists of psychological components including love, excitement, and tenderness, which are key factors associated with overall mental, physical, and emotional health in humans [5]. Meanwhile, raising a child is a complicated process that involves the promotion and support of the physical, emotional, social, and cognitive development from infancy to adulthood. This complexity of sexuality/sexual expression and parenting might influence people's perception of PID's inability to manage the factor of "parenting." There is an increasing recognition that PID experience parenting difficulties not solely because of the limitation resulted from their cognitive functioning. Indeed, numerous past and present parent, child, and family ecological factors will affect one's parenting style and child's outcomes in families where the parent has intellectual disabilities [51].

Methodology Applied and its Limitations

Regarding the methodology of the reviewed papers, sampling may be a concern. Except for one paper which employed a randomized technique [20], all the participants of the other studies were recruited by convenience sampling. A common concern is that the features of a given convenient sample may diverge from a representative population sample that could bias the findings. The opportunity to participate, which is not equal for all qualified individuals in the target population might influence the study results that could diminish generalizability. A central challenge for population-based survey experiments, however, is the cost. Conducting a randomized sampling study is commonly a challenge for a research team. Regarding the generalizability, according to the study conducted by Mullinix et al., nevertheless, there was a considerable similarity between many treatment effects obtained from convenient and nationally representative population-based samples [52].

In addition to the concern regarding sampling, the accepting attitude of the public towards the sexuality of PID requires further investigation. According to a study carried out by Guerra, when asked about participants their attitudes towards their own sexual behavior, the results were more restrictive whereas their attitudes towards others' sexual behavior were more accepting [53]. The reviewed papers in this study did not reveal personal attitudes towards sexuality. The findings thus cannot verify that the

accepting opinions as expressed by the participants were socially desirable answers or attitudes consistent with personal values. The consistency of personal values and attitudes towards PID regarding sexuality among parents and service providers particularly warrants further investigation. Since parents are important coaches of PID while service providers are important messengers, it is crucial to understand the mechanism why these two groups of individuals tend to hold a restrictive attitude.

Among the tools used to collect opinions from the participants, a questionnaire was found to be the most favored. Among the 11 reviewed papers, six of the studies used the Attitudes to Sexuality Questionnaire Individual with an Intellectual Disability (ASQ-ID) developed by Cuskelly et al. [18]. Although the ASQ-ID can somehow be considered as a “gold standard” for the evaluation of individuals’ opinions on the sexuality of PID and can be used for cross-population comparison, skewing to the use of a single instrument reflects that people’s attitude towards sexuality of PID is an area still under research by academics and clinicians. In addition, the Likert-type inventories in attempting to ascertain the extent to which participants agree or disagree with the sexuality as related to a PID is a method lacking much effort directed at uncovering the factors that may underlie the particular attitudes, for example, stigmatizing attitudes towards PID. Among the reviewed papers, only two out of 11 assessed the previous social contact experience with PID [21] or employed a scale to measure the attitude towards PID [16]. Thus, further investigation in the area of social contact or stigmatizing attitude towards PID is needed.

Meanwhile, the present review also highlights the need for adopting alternative research designs for the study of people’s attitudes. Only one study among the 11 reviewed papers evaluated the influence of the cultural orientation of the participants and its impact on the attitude towards the sexuality of PID [25]. Research on attitudes has taken the “individual self” as both the starting-point and the focus of analysis. However, it is also essential to articulate how social interaction makes psychological processes the way they are. Indeed, the majority of the reviewed studies employed conventional/classical quantitative research designs and investigated individualistic opinions. Borrowing the social constructivist’s lens, there is an interdependence of the “individual” and “society.” In other words, attitudes should not be viewed as solely personal or individual, but as arising out of interactions with others in the system [54]. Attitude is context dependent and responsive to factors within a particular sociocultural environment, so future research would benefit from employing alternative methods, such as life history or narrative interview to examine participants’ attitudes. From this “emic” perspective, findings can lead to leveraging the understanding of sexuality of PID inside a local organizational culture and interrelated processes of personal experiences, attitudes, and practices [55, 56].

The participants in the reviewed papers may have multiple interpretations of the label “intellectual disabilities” which occur when people attribute different characteristics to the label based on their experience. The extent of the general public having an ‘adequate’ understanding of intellectual disabilities is not clear. Research has also illustrated the widespread impact of social norms, roles, and policies on individuals’ experience and perception of health problems [57]. The problem of multiple interpretations can be alleviated by providing specific descriptions in the form of vignettes to illustrate the behaviors and characteristics of PID, rather than referring to a group of individuals by providing some disabling terminology [58]. In the present review, however, only two of the reviewed papers [19, 23] employed such approach to show some vignettes about PID to the participants.

Limitations

The analysis in this study was based on findings from other studies to examine the range of issues or categorical factors emerging from the data. The authors are aware of the fact that more relevant articles and research reports could exist other than in the searched databases. Further empirical research with specific attention to the sexual lives of PID, which collects data directly from various parties such as PID, parents, and service providers, is essential. To examine the interwoven interaction among these parties would also be a cherished enrichment to add knowledge to the scientific field and informing practitioners about service development.

Conclusion

People with intellectual disabilities share the same human need for affectionate and intimate relationships as those without disabilities. Based on the review, people, including general public, parents of PID and care staff were holding both restrictive and accepting attitudes towards the sexuality of PID. But generally, the attitudes of parents of PID or care staff were less permissive than the general public. Promoting the sexuality of PID is a challenging task. Further research with specific attention to people with intellectual disabilities, their family and service providers' experiences and challenges in the area is particularly essential. In addition, further research may also contribute to providing direction and insight for policymakers in regard to handling the social, legal and ethical concerns about the sexuality of PID.

Compliance with Ethical Standards

Conflict of interest The authors Angus Lam, Matthew Yau, Richard C Franklin, and Peter A Leggat declares that they have no conflict of interest.

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Chapter Conclusive Summary

This chapter provides an understanding on the public opinion on the sexuality of people with intellectual disabilities. Public members acknowledged that people with intellectual disabilities are not asexual. Demographic background and the conditions of people with intellectual disabilities were found to have an influence on people's attitudes. In addition, the public holds a more accepting attitude towards the sexuality of people with intellectual disabilities when compare with family or care staff.

Combining the findings from chapter two, in order to have an in-depth understanding on the sexuality of people with intellectual disabilities, it is essential to conduct empirical research with specific attention to the sexual lives of people with intellectual disabilities, which collects data directly from people with intellectual disabilities, parents, and service providers. The examination on the interwoven interaction among these parties would be a cherished enrichment to add knowledge to the scientific field and informing practitioners about service development. The next chapter will describe the methodological approach adopted in this doctoral study.

Chapter Four

Design: the methodology to explore the tripartite dynamic in handling the sexuality of people with intellectual disabilities

Chapter overview

The purpose of this study is to explore the tripartite dynamic in the handling of sexuality between people with intellectual disabilities, parent, and social services staff. The beginning of this chapter situates the author within the doctoral study and acknowledges the questions that informed the study. Subsequently, the chapter provides an overview of the methodological approach and the strategy employed to establish the trustworthiness on the narrative data collected. The research methodology stemmed from the focus of exploring the dynamic of how the three parties handle the sexual need of people with intellectual disabilities. This required a methodology that would enable the analysis of meaning about sexuality in a particular social-cultural environment. Pluralistic approach combining the application of Interpretative Phenomenological Analysis (IPA) and Dramaturgy analysis is best suited for the study and justification of this approach will be given in the middle of this chapter. The latter section of this chapter will provide details on the ethical approval related to the doctoral study. As the findings from the doctoral study are contained within papers and each paper consists of an introduction, methods, results, discussion, and conclusion sections outlining the specific approaches for each of these papers, detailed information about the methodology: data collection, result, and analysis, pertaining to each phase of the doctoral study is covered within chapter 5, 6 and 7 as these chapters are based on the published manuscripts.

Situating the Researcher

The author holds dual professional qualifications as a social worker and occupational therapist with predominant clinical experience in the field of rehabilitation for people with intellectual disabilities, mainly in vocational counselling and management of residential services. In addition to those practicing experiences, the author also has experience in counselling for parenting stress, and a postgraduate degree in mental health. Prior to commencing the research, the author undertook further training in sex therapy. After obtaining qualification as certified sex therapist, the author started to deliver structured sex education and training for people with intellectual disabilities, their parents, and related social services staff. The author's cross disciplinary professional training and working experiences sparked an interest in exploring what can be regarded as a tripartite alliance among people with intellectual disabilities, parents, and social services staff and how this alliance handles the sexual needs of people with intellectual disabilities. Apart from the clinical perspective, work experiences in various Chinese settings, and training in social science, have sparked the interest of the author to explore how culture and society construct meanings about sexuality. Regarding culture, the author of this thesis was born and has been brought up in a Chinese socio-cultural environment. The author has been socialized to the emic perspective of that culture: Confucian, paternalism in family, the social system, and witnessing how the media portrayed sex. The author acquired a world view which provides an insiders' perspective on culture, provides an indigenous insight to cultural standards, and helps with viewing the Chinese cultural nuances and complexities (Pike, 1990; Zhu & Bargiela-Chinppini, 2013; Faust, 2018). It further leads the author to focus on how Chinese culture correlates, or even influences, the tripartite relationship in the context of handling the sexual need of people with intellectual disabilities.

Questions Underpinning the Research

Research often begins with a personal interest or motivation, and literature review helps to consolidate that interest as a research topic, identify gaps and formulate research question(s) (Frost, 2011). As mentioned above, the author's background has led to the interest in conducting the research. The two literatures reviews in chapter 2 and chapter 3, provided information that people with intellectual disabilities are not asexual, and parents and health care staff comparatively held a conservative attitude towards the sexuality of people with intellectual disabilities. The conservative attitude perhaps did not deliberately come from parents and health care staff, but a control instigated by an "invisible hand".

Qualitative research is not necessarily looking to resolve any problem or tensions, but instead, aims to constructively explore them. For example, what do the participants of this research tell us about the phenomenon? What do they tell us about the people, groups, and reaction to the sexuality of people with intellectual disabilities? How do the contradictions, if any, point us to new areas of research? In qualitative research, this kind of question is very important and should be the guide for the research (Mason, 2006).

Based on the aforementioned, several questions underpinned this research and are acknowledged, as follows:

- a) Would there be any concern if people with intellectual disabilities express their sexual need or desire for intimate relationship to parent or service providers?
- b) What would be the feeling of people with intellectual disabilities if their sexual need expression is being ignored or acknowledged?

c) Would there be any concerns for the parents and service providers to allow or restrict people with intellectual disabilities to show any sexual behaviours, or express the need to have intimate relationship?

d) How would the tripartite interaction be displayed regarding the sexual needs and intimate relationship of people with intellectual disabilities?

e) How would the social context be influencing the tripartite interaction regarding the sexual needs and intimate relationship of people with intellectual disabilities?

Research methodology

The research methodology includes methods, theoretical approaches, techniques for data collection and analysis. Research methodology is a master plan detailing the methods and procedures for collecting and analysing the required information and data collected (Mouton, 2001; Zikmund, 2003). The following section explains the rationale of choosing qualitative method and the background of theoretical framework.

Rationale for choosing qualitative methods and theoretical perspective

The Likert-type inventories commonly used in quantitative research when attempting to ascertain the extent to which participants agree or disagree with an opinion does not identify the factors which underlie the respondent's attitude. This kind of method, in the context of studying sexuality for people with intellectual disabilities, for example, to what extent do people agree with the notion that 'people with intellectual disabilities' have the right to enjoy their sexual life, is believed to have difficulty at uncovering the factors that potentially underlie the respondent's attitudes (Avramidis & Norwich, 2002). Thus, it is not easy to quantify the

meanings about sexuality from the perspective of people with intellectual disabilities, and the impact of parental attitudes on the topic area. In addition, it has been difficult to create a monolithic image of a typical parent or a social service staff in the context of handling the sexual need of people with intellectual disabilities. Instead, the qualitative methodology used in this research should enable the analysis of how multiple factors alter the behaviour and attitude of sexuality of people with intellectual disabilities, and the two significant others: parents and social services staff.

Research can begin with initial thoughts of an area of interest. These thoughts become crystallised as further consideration is given by further review of the literature (Jackson, 2013). According to the review of the literature in chapter 2 and 3 of this thesis, people with intellectual disabilities experience the same spectrum of sexual expression as ordinary people: from abstinence to liberty (Lam et al., 2019). Families and social service staff have a dual responsibility to empower and protect people with intellectual disabilities in terms of matters related to sexuality. Although parents tend to be the most influential and consistent coaches of people with intellectual disabilities, social services staff can also play a role in the communication of appropriate information (Lam et al., 2021; Koolen et al., 2019). The attitude of significant others is one of the obstacles people with intellectual disabilities need to address to maximize their own sexual potential in terms of sexual health, dating or entering a relationship, having sexual intercourse or procreating (Evan et al. 2009). In addition, obstacles to hinder the sexual potential of people with intellectual disabilities may be related to cultural norms, negative attitudes, beliefs and feelings of parents and social service staff (So & Cheung, 2005; Yau et al., 2009; Lam et al., 2019).

Creswell (2018) states that qualitative research is conducted when a problem needs to be “explored”. This exploration echoes to the need of people or variables that cannot be easily measured, or to hear the “silenced voices”. Qualitative method is essential and crucial, which fosters a rich understanding of individual experiences but also shed light on the way in which these experiences are constructed and modulated by societal expectations and social interactions. Qualitative research also relies heavily on theories drawn from the social sciences and humanities to guide their research process and illuminate their findings (Reeves et al., 2008).

The pluralistic approach is the application of more than one qualitative analytical method to produce multiple, complex, and varied understandings of phenomena (Frost et al., 2011; Clark et al., 2015). Within the pluralistic approach, study design can provide a dual lens with which to explore qualitative information, which is interpreted both as lived experience, and as structural relations through which those meanings are produced (Hood, 2015). Considering the research will examine personal experience about sexuality of people with intellectual disabilities, and investigate the dynamic relationship of the three groups of participants under the Chinese socio-cultural environment, it is appropriate to adopt such an approach through the consideration of two independent but interlinked methodologies, i.e. interpretative phenomenological analysis (IPA) and dramaturgical perspective.

Interpretative Phenomenological Analysis (IPA), one of the theoretical approaches commonly used by qualitative researchers in health domains, is a philosophical approach to identify an “object” of human experience (van Manen, 1990) and “the way in which things are perceived as they appear to consciousness” (Landridge, 2007). One of the strengths of IPA is

for examining topics which are complex, ambiguous and emotionally laden. (Smith & Osborn, 2015). Given the focus of tripartite interaction in this research, the adoption of a dramaturgical perspective was of considerable value in shaping the research design. Dramaturgy is a particular strand of symbolic interactionism that utilises the metaphor of the theatre as a means of understanding social processes and human interactions (Goffman, 1959; Appelrouth & Edles, 2016).

Interpretative Phenomenological Analysis (IPA)

Interpretative phenomenological analysis (IPA) is a qualitative approach. It developed within psychology for the investigation of personal lived experience, based on the principle that there is a phenomenon out there ready to be explored (Smith, 1996). The investigation requires researchers to bring the phenomenon to light by using their prior experience, assumptions, or preconceptions to make sense of the experience once it is revealed (Smith et al, 2009). IPA has two primary aims: to look in detail at how someone is making sense of life experiences, and to give detailed interpretation of the account to understand and interpret the experiences of people (Shinebourne & Smith, 2009; Shinebourne & Smith, 2010). Hermeneutics, one of the major theoretical underpinnings of IPA, emphasizes the art and science of interpretation or meaning (Smith, 2016). Meaning in this context is deemed as something fluid that is continuously open to new insight, revision, interpretation, and reinterpretation (Henriksson et al., 2012). IPA also employs the idea from Heidegger, of ‘an influential philosopher’, to advance the thesis of hermeneutic phenomenology (Tuffour, 2017). Heidegger has argued that the primary concern for existential phenomenologists is to investigate and interpret existence as it is humanly experienced (Spinelli, 2005). IPA is also influenced by symbolic interactionism (Eatough & Smith, 2008). Symbolic interactionism provides a theoretical perspective with basic assumptions that people act on the basis of the

meanings that things have for them, and those meanings emerge in the processes of social interaction between people (Blumer, 1969). This structured approach and qualitative orientation seems to appeal to other disciplines in human, social and health care, and sexuality research (Smith, et al., 2009; Finlay, 2011).

For understanding healthcare and illness from the patient or service user perspective, IPA draws on a similar body of philosophical influences to the existential approach, but the analytic processes and outcomes are rather different (Pringle, 2011). The IPA researchers studying via what Heidegger terms as “throw-ness” by immersing themselves in the world of the participants through a lens of cultural and socio historical connotations (Moran, 2000). It is about the pre-existing world of people and objects, language, and culture, and cannot be meaningfully detached from it. Further, IPA operates with a double hermeneutic, as the researchers collect detailed, reflective, first-person accounts from research participants, then try to make sense of the participants’ experience and trying to make sense of their world as well (Larkin & Thompson, 2012; Smith & Osborn, 2015).

Interpretative phenomenological analysis particularly fits the research to investigate a sensitive topic like sexuality. The outcome of a successful IPA study is likely to include an element of ‘giving voice’, which emphasizes convergence and divergence of experiences, as well as examining detailed and nuanced analysis of the lived experience of participants. Further, success of IPA is about ‘making sense’, which includes offering an interpretation of the voices of research participants (Larkin et al., 2006). Therefore, the researcher assumes a central role in analysing and interpreting the participants’ experiences and intuitively seeking to probe the surface meanings by reading in between the lines for deeper interpretation (Finlay, 2011). In

addition, IPA researchers realize this chain of connection is complicated – people struggle to express what they are thinking and feeling, there may be reasons why they do not wish to self-disclose, and the researcher has to interpret people’s mental and emotional state from what they say (Smith & Osborn, 2003). IPA is a relatively accessible qualitative approach – and there are lots of published examples and methods articles to draw upon – but striking the right balance between these two key components takes considerable time and effort. This is often best conducted in the context of supervision and peer support, which can facilitate the development and discussion of these elements (Larkin & Thompson, 2012).

Data for IPA should be obtained from a purposive and homogeneous sample (Tuffour, 2017). The comparatively smaller number of participants allows for a richer and deeper analysis which might be hindered by a larger sample (Smith et al., 2009; Pringle, 2011). Indeed, quotes and metaphors used by participants can also be used in theme titles or descriptions of the evidence to further place the analysis directly in their words. In other words, IPA research goes beyond a standard thematic analysis (Brocki & Wearden, 2006). The most common data collection method is the in-depth semi-structured interview (Hennink et al., 2020). While the researcher starts with a research question and interview schedule, this is used flexibly during the interview as the participant is probed on issues arising. Interviews are transcribed and then subjected to an idiographic qualitative analysis, looking in detail for experiential themes case by case and then for patterns across cases (Eatough & Smith, 2006).

In summary, IPA has a solid philosophical foundation. It takes active steps to give voice to the experiences of the participants, following with sufficient interpretation of their narratives. IPA is fundamentally a subjective research approach specifically offers flexible and versatile

way to understand people's experiences (Tuffour, 2017). It is suitable for examining the experience about sexuality of each group of participants proposed to be involved in this study.

Dramaturgy and symbolic interactionism

Both IPA and dramaturgical perspective have the connection with symbolic interactionism (Muchena et al., 2018). Interactionist themes: symbols, shared meaning, and identity, are found throughout Goffman's work. All these elements have spanned multiple decades and influenced a legion of sociologists. To this day, Goffman continues to be one of the most inspirational and cited sociologists (Carter & Fuller, 2016).

Symbolic interactionist perspectives emerged in the United States in the early decades of the 20th century. It is a micro-level theoretical framework and perspective in sociology that addressing how society is created and maintained through repeated interactions among individuals (Brickell, 2006; Carter & Fuller, 2016). It presumes meaning to be an emergent property of human interactions, not something intrinsic to an individual or a situation. Accordingly, people construct the meaning of their social world and their own lives through daily interactions with other people, gathering together, and negotiating meaning as people participate in social life (Blumer, 1969). Symbolic interactionism is increasingly influential in contemporary informatic and media predominant world (Shulman, 2017). Symbolic interactionists ask how people present themselves within particular "interaction orders", that is, domains of social interchange governed by rules and conditions (Goffman, 1959, 1983; Hardey, 2002). Subjects manage impressions of themselves in the presence of others and conduct themselves in ways that demonstrate their competence within an interaction order. By manipulating photos, texts and chat messages used in media, subjects try to obey those

corporeal rules that allow them to ‘come across as credible’ (Vannini, 2004) and maintain a good overall impression (Zhao et al., 2008).

Goffman’s seminal book *The Presentation of Self in Everyday Life* (1959) used the metaphor of a theatrical performance as a framework to describe how actors presented themselves to others, and how they attempted to control others’ impressions to be seen positively. Goffman’s (1963a) later work on stigma addressed how those with ‘spoiled identities’ (e.g., those with physical deformities, drug addicts, prostitutes) had difficulty in negotiating their environment due to others’ hesitation or refusal in accepting them. Goffman’s work also addressed how rituals influence social interactions (Goffman, 1967), proper etiquette for behaving in public places (Goffman, 1963b), and how actors use frames to interpret reality and organize experience (Goffman, 1974). As one of the major schools in symbolic interactionism, the dramaturgical perspective has its subjective viewpoints on how individuals make sense of their world from their unique perspective. Symbolic interactionists are often less concerned with objective structure than with subjective meaning – how repeated, meaningful interactions among individuals come to define the makeup of ‘society’ (Carter & Fuller, 2016).

According to dramaturgical perspective, people generally attempt to project their own ‘definition of the situation’ upon social proceedings (Goffman, 1959). In so doing, people participate in the collective establishment of a ‘common world’ of understandings, albeit one that is liable to shift over time (Brickell, 2006). For example, Chinese may strive to present themselves as credible and competent members of Confucius’ society, in order to avoid adverse social judgement and sanction.

Symbolic interactionism and sexuality

Traces of interactionist ideas are apparent across sociological research, specifically from a dramaturgical perspective on individuals' identity and social roles (Goffman, 1959; Burke & Stets, 2009). Beyond these subfields, inquiry in symbolic interactionism include social problems (Best, 2003), cultural studies (Fine, 1996), gender and sexuality (Thorne, 1993). Starting from the late 1960s these general symbolic interactionist insights about meaning, subjectivity and interaction were applied to sexuality by John Gagnon and William Simon (Gagnon & Simon, 1973). These authors argued that our experience of sexuality is guided by patterned constellations of language and action, convention, and expectation. Society makes available 'cultural scenarios' which prescribe what and how of sexual conduct and its forms: with whom might one engage with sexually, why and when, and what might one expect to feel? From these scenarios individuals piece together sexual 'scripts', internalising and routinising wider sexual meanings and developing sexual 'careers' (Whittier & Simon, 2001). In this way, the individual's sexual world emerges at the intersection of meaning, subjective interpretation, and social interaction.

In the context of Chinese culture, the subject learns to regulate him or herself with respect to the expectations of the Confucius society, and he or she interiorizes this regulation (Danaher et al., 2000). This is governmentality, an 'art and science' that operates through customs, habits and reflexive ways of thinking and acting, and through which subjects learn to govern themselves (Foucault, 1991). The health advice that produces sexual knowledge has a strong governmental aspect, combining liberal discourses of self with remonstrations about good and compliant behaviours (Ryan, 2005).

In a nutshell, symbolic interactionism is a bridge connecting Interpretative Phenomenological Analysis (IPA) and dramaturgical perspective (Eatough & Smith, 2008; Carter & Fuller, 2016; Muchena et al., 2018). These two independent but interlinked approaches have their advantage in studying sexuality (Smith, Flowers, & Larkin, 2009; Thorne, 1993). In the Chinese context of a research project involving people with intellectual disabilities, parents and social services staff, the pluralistic approach blending the IPA and dramaturgy is believed to be a suitable method. It can support the examination of the individual experience about sexuality for each group of participants and investigate interaction among the three groups.

Participant Selection and Recruitment

Purposive sampling involves the researchers to select individuals who would have knowledge of the phenomena studied or deemed rich in potential information (Mapp, 2008). While sexuality is an “every human phenomenon”, the sample should cover parents, service providers, and people with intellectual disabilities of both genders and at various ages. People with intellectually disabilities are not a homogenous group (Kijak, 2011). As there is a delay of three years to the onset of the first menstruation and wet dreams, at around the age of 15, when compared with intellectually normal people (Kijak, 2011), the population of the proposed study focused on people with intellectual disabilities aged over 18 years, parents with adult children with intellectual disabilities, and social services staff working for people with intellectually disabilities. Considering interviews were the data collection method, only people with mild grade of intellectual disabilities were recruited. Research revealed that people with a mild grade of intellectual disabilities are able to express their needs and wants and participate in social communication (Nota et al., 2007; Bayes et al., 2013).

Comorbidity may require a diverse care and management approach to the individual (Copper et al., 2015), to focus on the investigation on the theme of sexuality and people with intellectual disabilities, parents with children with both intellectual and physical disabilities were excluded. As Chinese culture might play a role to influence individuals' concept of sexuality (Ho et al., 2018), the proposed study only recruited Chinese people to ensure the background of the participants share similar cultural experiences. This approach was in keeping with Creswell (2013), where it is appropriate for researchers to conduct interviews with 5 to 25 individuals who have all experienced the phenomenon. Thus, it was proposed that 24 participants in total to be recruited, comprising eight people with intellectual disabilities aged over 18, eight parents and eight social services staff.

The author has more than 20 years of working experience in the field of rehabilitation. With this background, the author contacted two non-government organizations (NGO) in the preliminary stage regarding the recruitment, one NGO is in Hong Kong and the other is in Macau which the major services are for people with intellectual disabilities. The author proposed to recruit participants from these two NGOs equally.

Inclusion and exclusion criteria

Inclusion criteria:

- a) People with mild grade of intellectual disabilities aged over 18;
- b) Parents/Caregiver of people with intellectual disabilities who are aged 18 or above;
- c) Staff of social services units providing services for people with intellectual disabilities who are aged 18 or above.

Exclusion criteria:

- a) People with intellectual disabilities comorbid with other disability; or
- b) Caregiver of people with both intellectual disabilities and physical disabilities, or
- c) Non-Chinese.

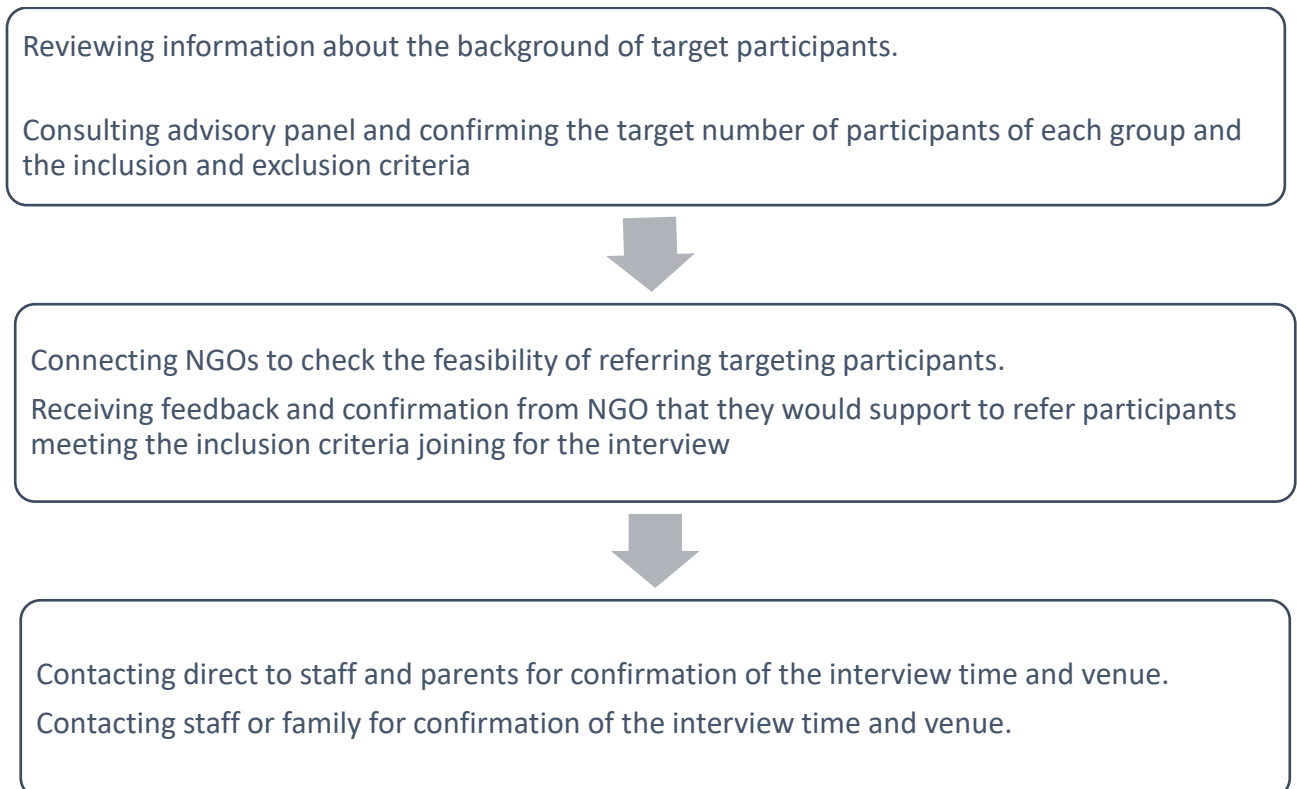


Figure 4.1 Workflow for participants' recruitment

Recruitment challenges and reflexivity

According to Burns and Grove (2007), a pilot study is a small-scale work in order to check and enrich the methodology, and pinpoint any possible problems prior to the formal start of the main study. Piloting interview questions were referred to Bevan's framework (2014) and were discussed within the research team and then recruited two participants from each party who met the inclusion criteria as a pilot test for the qualitative interview. Participants were

expected to be invited via NGOs, including hostel, sheltered workshop, and parent resource centre.

Table 4.1: Summary of progress of data collection

Year 2019	Year 2020			
Nov	First quarter	Second quarter	Third quarter	Fourth quarter
Ethics approval obtained	Pilot Interview	Interview was interrupted	Interview continued	

Recruitment was slower and somewhat more difficult than the author had planned. Interviews took approximately nine months to complete. Table 4.1 above shown the overview of progress of the participants' recruitment and interview. The major obstacle of recruitment was the COVID-19 pandemic which started early 2020. For piloting interview, one social services staff, who was a training assistant, one male with intellectual disabilities and a mother with two children with intellectual disabilities were interviewed. These interviews were undertaken face-to-face. As the Covid-19 pandemic started to become serious in Hong Kong in the middle of year 2020, people became concerned about the safety of participating in a face-to-face interview.

A face-to-face interview characterised by synchronous communication in time and place, is no doubt going to help to capture verbal and non-verbal cues, including intonation, body language, raw emotion and behaviours which can indicate a level of discomfort with the questions, particular in the context of discussing sensitive topic like sexuality (Edwards & Holland, 2013). Face-to-face interviews also assists the interviewer to control the interview and keep the interviewee focused and on track to completion, free from technological distractions. Considering these factors, the author of this thesis decided to extend the length of

recruitment period. Once any sign indicating the pandemic had slowed down, the author did proactively contact NGOs to recruit participants to take part in the interview.

The delay of participant recruitment had both pros and cons. It allowed the author to have more time revisiting the interviews verbatim and engaging in memo writing. This revision further helped to re-evaluate the interview schedule which assisted the author to better prepare for upcoming interviews. Thus, the author could explore particular lines of inquiry as needed to extend and refine the interpretation. Finally, having additional time for critically reviewing the interview schedule enabled the author to identify instances where any unintentionally missed, blocked or detoured from theme of discussion.

Owing to the travelling ban during the pandemic, interviews could not be done outside Hong Kong. Therefore, no participant was recruited in Macau. With the connection in Hong Kong NGOs, eventually seven social services staff employed by three different units, covering community and residential services were recruited. For parents' group, there were seven parents with adult child(ren) with intellectual disabilities who participated in the study. For the group of people with intellectual disabilities, considering the risk of infection, the recruitment in this part became very difficult. Eventually, only five people fulfilled the inclusion criteria and could be recruited. Details of the participants of each group are presented in the published findings papers (chapters 5, 6 and 7) in this thesis.

Data Collection

Individuals who were considered to have a good understanding of Cantonese and a level of comfort with this topic were invited. Prior to taking part in the one-to-one, in-depth interview,

participants signed the consent form. The author invited a female clinical psychologist to join the interview in case participants expressing concern with being interviewed by a male interviewer.

The data collection tool for semi-structured interviews is an interview schedule. The interview schedule was updated after the verbatim transcription of the pilot interviews has been undertaken, in order to accommodating new ideas which has arisen. Open-ended questions were used during interviews with the aims of obtaining detailed and rich information (Parahoo, 2006). The topics contained within the pilot interview schedule covered the followings domains:

- a) The experience of people with intellectual disabilities having sexual needs and their handling of these needs.
- b) The experience of people with intellectual disabilities interactions with their parents / social services staff in the context of handling their sexual needs.
- c) The family context (interactions with husband or wife about sex education, worries/concerns).
- d) The experience of managing the sexuality of people with intellectual disabilities in a social services and health care setting.
- e) The perception and feelings around sex education (parents and staff experiences, where the person with intellectual disabilities could get information, who should provide it).

Rapport building and formulation of interview question

Rapport building was crucial to support the establishment of a trusting relationship with participants. To enable participants to feel comfortable to impart information, particularly in the context of sexuality, all the interviews were conducted in a private interview room. Prior to the commencing of the interview, the author of this thesis introduced himself and engaged with each participant in small talk. Small talk, also termed “phatic communication” in the health and counselling professions, is engagement in ordinary conversation, for example, commenting on the weather, the traffic condition which helps in rapport building and promotes atmosphere of equality and belonging (Crawford et al., 2006). The author also introduced potentially less intrusive or more basic topics at the beginning of the interview, with potentially more sensitive and complex topics discussed later in the interview, this will be discussed below.

All interviews were semi-structured. Interview questions were developed based on professional knowledge in sex therapy, clinical experience of the author, literature reviews and methodological literature on the development of IPA interview schedules. A “funnelling technique” informed the interview schedule which enabled the interview to move from general topics to more specific themes (Smith & Shinebourne, 2012; Noon, 2018; O’Sullivan et al., 2020). This type of schedule provides structure but also allows for the emergence of rich data while maintaining consistency across participants. For example, a question for social service staff would be: “Would you please tell me your duty in working with people with intellectual disabilities?”; “In general, have you experienced any difficulties in your daily work?”. An example for parents would be: “Would you please tell me about your usual life with your child with intellectual disabilities”. For the group of people with intellectual disabilities, the initial questions were: “Would you please tell me about living in the hostel?” or “Would you please tell me about your work?” This technique is particularly important for this study. Even in a

healthcare setting, talking about sex can be a sensitive and awkward topic generating embarrassment among practitioners (Ollivier et al., 2019). The consideration of having awkward feeling when discussing sexuality should be applied to all including people with intellectual disabilities, parents, and the researcher as well. Hence, funnelling is particularly important for this study.

Subsequently, the interview evolved and developed a more specific line of questioning related to the experience of the sexual needs of people with intellectual disabilities. For instance, for social service staff: “What specific tasks in sex education or dealing with sexuality have you delivered to people with intellectual disabilities?”; “Have you ever encountered any difficulties when you were trying to tackle this issue?”; “How did you feel when you experience this type of difficulty?”. For the group with people with intellectual disabilities, the questions were: “Have you met anyone in your workplace/hostel that you fell in love with?” “Have you browsed any materials/websites related to sex?”

This approach enabled the authors to glean a more holistic understanding of participants’ experiences in dealing with the sexual needs of people with intellectual disabilities. The next part of the interview, culminates in a more specific line of questioning related to the experience of romantic relationships or experiences related to sexuality of people with intellectual disabilities.

Data Analysis

A triangulation team approach, involving the author and supported by advisors, enabled a triangulation method, and resulted in theme consensus within the team. The author designed the structure of the doctoral study under advisors' guidance, and completed data analysis, with analysis checking completed by the advisors. Peer debriefing was used, whereby the researcher discussed the analysis, including themes that were emerging from the data, with the advisors. This "critical friend" approach enabled discussion, reflection, and critical feedback on the analysis (Smith & McGannon, 2018; Helen & Roberta, 2019).

Figure 4.2 Triangulation and stage of data analysis

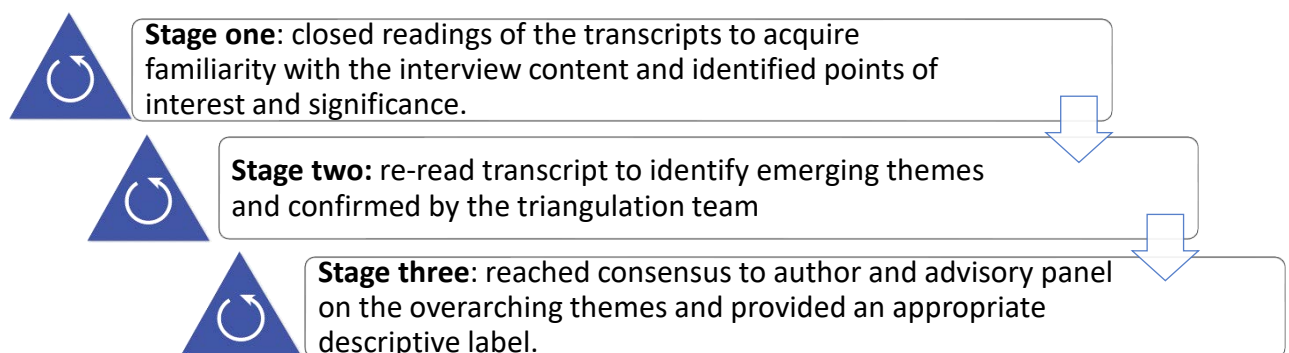


Figure 4.2 shows the stage of data analysis (Smith & Osborn, 2008). The three hierarchical boxes illustrate the major tasks of the different stages of data analysis. The three blue triangles with circuitous arrow illustrate the triangular discussion in each stage of data analysis. The audiotaped interviews were transcribed verbatim in Chinese to preserve the details of the information. The main task for stage 1 was to cover numerous close readings of the transcripts for acquiring familiarity with the interview content. The author then read the transcribed data line by line to identify points of interest and significance. In Stage 2, the transcripts were re-read for identifying emerging themes. Those themes were translated from

Chinese into English and were endorsed by the primary advisor, who is a bilingual academic and sex therapist. All these themes eventually obtained confirmation by the author and advisors. In Stage 3, a set of emergent and linking themes and supporting verbatim quotes was compiled. Coding of emergent themes and their further refinement led to the development of super-ordinate and associated sub-ordinate themes. Independent verification that the author's interpretations were grounded in the data was secured through checking of developing analysis by getting advice from advisors. Finally, author and advisors reached consensus to group these into overarching themes and provided an appropriate descriptive label in English.

Data analysis utilised Interpretative Phenomenological Analysis (IPA) and dramaturgical perspective. Interpretative phenomenological analysis recognises the active engagement of the researcher in attempting to understand the participants' world (Blyth, 2012). Crucially, IPA helps to interpret the data generated, rather than assumes researcher "objectivity". IPA acknowledges participants' expertise as regards to their own experiences and facilitates the discovery of knowledge from their cognitions, narratives and behaviours as described in their own words. For dramaturgy, it critiques social interaction and reveals the form and strategy of human action as drama (Hunt & Benford, 1997). This analytic technique is ideal for investigating the influence of cultural values on day-to-day life, between different group of people (Reybold & Halx, 2018).

Ethical Considerations

Qualitative research involving people with intellectual disabilities often assumed to be particularly ethically challenging because of their potential vulnerability. The topic covers

sexuality would add further considerations to the ethical board and recruitment process, in particular using interview as a way for data collection.

Ethical approval

The participants of the project were Chinese and the data collection for the project took place in Hong Kong. Considering the requirement for research and concern from local NGOs, the author of this thesis submitted the application to the Research Ethics Committee, Tung Wah College, the institute that the author and primary supervisor are currently employed. The approval was received on 26 Nov 2019 (REC2019049) with one extension approved till 28 Feb 2021 due to the delay of data collection induced by the pandemic. According to the “Application Guide: Human Research Ethics”, a research project has been approved by an external committee recognised within that country, it is not necessary to submit an application to the James Cook University Human Research Ethics Committee. But an external approval must be submitted to and sign by dean of college. The project subsequently received external approval from the school dean of College of Public Health, Medical and Veterinary Sciences of James Cook University (Appendix A).

Informed consent

Prior to the interviews, potential participants were provided with a Participant Information Sheet and Consent Form and given time to read through this sheet and discuss any questions that they may have had in relation to the research. As part of the process, the author emphasised to participants of the parents and social service staff group that they were not obliged to take part in the study and that they had the right to withdraw from the study at any point.

For the people with intellectual disabilities and their parents, the author further explained that their decision to participate or not, would have no impact upon the nature of the care received through social services. In particular, for the group of people with intellectual disabilities, special and additional consideration, based on the idea of Wark et al., (2017) is applied. Prior to the start of the interview, all the people with intellectual disabilities were told and were ensured to understand the following principles:

- a) The individual understood they were being asked questions about their levels of satisfaction with regard to the support they received from the organisation.
- b) They understood that they did not have to participate in the interview.
- c) They understood that they could have a support person present (female clinical psychologist, social services staff, family member), but, equally, they also understood that they could choose not to have a support person present.
- d) They understood that they could choose not to answer some questions.
- e) They understood that they could stop at any point, either to resume at a later stage or to withdraw completely. They understood that there would not be any consequences, regardless of their decision to participate or not, and irrespective of what answers they gave.
- f) They were able to clearly indicate that they wanted to participate, through whatever mechanism was appropriate for their individual circumstances.

All participants were subsequently asked to sign, indicating that they understood the study and wished to be involved. For people with intellectual disabilities, their caregiver or social services staff had presented as a witness for signing the consent form.

Confidentiality and anonymity

Participants' confidentiality and anonymity were maintained at all times through the research process. To ensure this, the author took the following specific steps:

- a) An identifying code was allocated to interview recordings to remove the need for personal identification in transcripts.
- b) Electronic copies of recorded interviews were copied to a secure, password-protected university server immediately following each interview. The audio files were then deleted from the digital recorder.
- c) A confidentiality agreement was signed by the paid transcription provider, prior to recordings being sent for transcription.
- d) Once the author received typed transcripts, all potentially identifiable details of participants and/or other individuals (such as friends, health professionals etc.) were altered in the transcripts.
- e) Identifying codes (rather than names) were (and will continue to be) used in all published materials and presentations. For example, for social services staff group, participants were identified as S1, S2; for people with intellectual disabilities, participants were identified as ID1, ID2; for parent group, participants were identified as P1, P2.
- f) Information regarding which participants consented to partake in the study was not communicated to staff within the social services unit.
- g) Consent forms have been digitalised and stored in the Tung Wah College secure repository where they will be retained for 7 years. All raw data pertaining to the project has been stored electronically on a password-protected university server. This data will be kept for five years following completion of this research, after which time it will be deleted.

Protection from harm

Given the sensitive nature of the topics discussed during interviews, there were potential feelings, e.g., embarrassment, could be evoked during the interview. For this reason, a private interview room was arranged either in Tung Wah College, or the social services units. For people with intellectual disabilities, family member and / or social services staff were allowed to participate in the interview, if the person with intellectual disabilities gave consent to do so. In addition, the author arranged a female clinical psychologist with experience working for people intellectual disabilities to be available to provide support and counselling to any female participants when needed during an interview; only one female participant with intellectual disabilities indicated that this was required.

Chapter Conclusive Summary

Methodology is the compass of a research project. This chapter highlighted the background of the author situating in the study. The rationale of pluralistic approach and the application of interpretative phenomenological analysis and dramaturgy were given. The sampling method, data collection and triangulation strategies for analysis were explained as well with the support by figures and table. Ethics and protection participants from harm are crucial for research, particular the research project touches on sexuality of people with mild grade of intellectual disabilities. All these issues were addressed in the latter part of this chapter.

The next three chapters will present the finding from tripartite group. Chapter 5 will give details on the analysis of the data collected from people with intellectual disabilities. For parents and social services group, the findings will be presented in chapter 6 and 7, respectively.

Chapter Five

Struggle: the sexual need and the experience of people with intellectual disabilities to have intimate relationship

Chapter overview

This chapter presents findings from interviews with people with intellectual disabilities and focuses on their experience about sexuality and intimate relationship. Five people with mild grade intellectual disabilities expressed their experiences and difficulties in having sex or engage in a relationship. Two overarching themes, “understanding” and “doing” on sex issues are identified. Same as the findings in previous chapter, Chinese culture is believed to play a role to influence the two overarching themes found in this section.

Chapter structure

This section is based on a publication (Publication 3) in the *Sexuality and Disability*. The paper as in the format of the journal article will be presented in the next page. Prior to the end of the chapter, a conclusive summary would be given.

Citation of the paper: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2022). People with intellectual disabilities struggle to have a sexual encounter: a Chinese cultural context investigation. *Sexuality and Disability*, 40, 245–260. <https://doi.org/10.1007/s11195-022-09733-3>



People with Intellectual Disabilities Struggle to have a Sexual Encounter: A Chinese Cultural Context Investigation

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Accepted: 16 March 2022

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Abstract

People with intellectual disabilities share the same human need for affectionate and intimate relationships as people without a disability. Limited research has investigated sexual issues and concerns among adults with intellectual disabilities, including dating, intimate relationships, and marriage. This study employed Interpretative Phenomenological Analysis to identify the understanding and needs regarding sexuality of people with intellectual disabilities. Five people with mild grade intellectual disabilities participated in face-to-face interviews in which they discussed their struggle to have romantic relationships and sexual encounters. Their “understanding” and “doing” on sex issues were identified. The lack of adequate sex education and Chinese culture potentially impact people with intellectual disabilities’ beliefs and behaviors on sexuality. Various types of intervention were discussed. Further research is necessary to understand the cultural context of the challenges and experiences regarding sexuality faced by people with intellectual disabilities and their families.

Keywords Intellectual disabilities · Sexuality · Chinese culture

Introduction

People with intellectual disabilities share the same human need for affectionate and intimate relationships as their peers without a disability [1]. People with mild or moderate intellectual disabilities are capable of and show a desire for sexual and intimate relationships [2, 3] and are also able to talk about sexual intercourse with a loved one as a mutually enjoyable experience [3]. However, false assumptions about sexuality and sexual relationships regarding people with intellectual disabilities persist. First, some may perceive that people with intellectual disabilities require protection from sexuality because they are considered ‘eternal children’ [4] and have no sexual feelings [5]. Secondly, some may have the negative attitude that people with intellectual disabilities

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should be in segregated institutions and that sterilization should be imposed to prevent people with intellectual disabilities from reproducing [6]. While some research suggests that some people have liberal attitudes regarding the sexuality of people with intellectual disabilities [7, 8], other studies reveal that the social networks of people with intellectual disabilities are often more restricted than those of the general population [9]. Hence, people with intellectual disabilities are potentially socially isolated and do not have the same opportunities to develop and engage in a romantic relationship. Their opportunities for expressing sexuality further remain limited and controlled by others [10]. A review paper highlights the prejudices of care staff and parents across different countries as consistently blocking the empowerment of people with intellectual disabilities regarding sexuality [11].

Traditional ideologies and folk concepts remain influential for contemporary views on sexuality [12]. The neo-Confucian premise emerged around 1000 A.D. and continues to influence the contemporary Chinese concept of sexuality. Confucian teaching has been re-interpreted to denounce sexual intimacy and pleasure. Confucianism views sex as harmful to physical health and spiritual pursuit, not a subject for social discussion, valuing sexuality for reproduction but not for seeking sexual pleasure, and instructing people to cover their body to the neck [4, 13, 14]. Since the 1950s, Confucianism in Mainland China suffered a steady decline as the new regime explicitly sought to replace it with the new state orthodoxy of communism. However, “New Confucianism” remains a potent force in Chinese societies, such as Taiwan and Hong Kong [15]. Confucianism is emphasized in various aspects of life, including arts, history, social life and government. Confucian values have been passed down the generations through the education system [16]. Hong Kong is considered as ‘Asia’s world city’ and the most westernized Chinese society. However, Confucianist values set it apart from its peer international cities. Although Hong Kong has a booming sex market offering services such as love hotels, online sex workers and dating services [17], sexuality is not openly discussed or expressed but is often talked about in an ambivalent or implicit way [18, 19]. As befitting a city where “East meets West” Hong Kong’s many decades as a British colony have resulted in the indigenous population’s absorption of Christian values and practices alongside traditional beliefs, influencing the delivery of sex education. Christian ideas about sex, including denunciation of sexual pleasure, the love-marriage-sex trilogy and the monogamous marital system, were further promoted through colonial administration, legislation, mass media and religious activities [4].

There is limited research on how people with intellectual disabilities respond to and perceive sexuality in this context. However, it is important to identify sexual issues and concerns among adults with intellectual disabilities, including dating, intimate relationships, and marriage [4]. Furthermore, human attitudes and feelings are context-dependent and responsive to factors within a particular sociocultural environment. Specifically, considering the local organizational culture and interrelated processes of personal experiences, attitudes in a social environment for people with intellectual disabilities could enhance understanding of sexuality issues related to them. To examine this, the emic approach that centers on participants’ perspectives and examines the research setting by describing participants’ ways of communicating, behaving, and interacting in the social context is recommended [20–22].

This article reports the findings of a qualitative study to explore the experiences of people with intellectual disabilities on their need for an intimate or romantic relationship and sexual expression. The article also discusses sociocultural factors that potentially influence these experiences.

Methodology

A qualitative approach using semi-structured interviews based on Interpretative Phenomenological Analysis (IPA) [23] was chosen. IPA has its theoretical origins in phenomenology, idiography and hermeneutics: a focus on experience, the particular and interpretation. IPA is usually conducted with relatively small samples, aiming to balance in-depth analysis with individual cases and exploration of a full range of issues across the sample [24]. Specifically, a key advantage of IPA is that it allows the researcher to examine and interpret the understanding and experience of people with intellectual disabilities in receiving information about sex or expressing their sexual needs. A semi-structured interview was scheduled containing open-ended, non-directive questions. Smith and Osborn [25] note that formulating a schedule leads IPA researchers to explicitly consider their expectations in the interview and enable them to identify any potential difficulties in terms of question wording or sensitive topics.

The interview approach for constructing the schedule was funneling [26]. This technique is particularly important for this study. This design aims to enhance memory recall by starting with broad questions to obtain as much information as possible, for example: “Would you please tell me about living in the hostel?” or “Would you please tell me about your work?” Subsequently, the interview culminates in a more specific line of questioning related to the experience of romantic relationships or experiences related to sexuality, such as: “Have you met anyone in your workplace/hostel that you fell in love with?” “Have you looked at any materials/websites related to sex?” This approach assists the researcher to glean a more holistic understanding of the context of participants’ experiences related to intimate relationships and sexuality.

The study received approval from the College’s Research Ethics Committee (REC2019049) as a low-risk proposal. The first author contacted two local NGOs and requested case social workers to identify individuals aged over 18 years diagnosed with mild grade intellectual disabilities to take part in the study. Five participants were recruited. One participant signed the consent form that was witnessed by his brother. For the rest of the participants, the consent was signed witnessed by the case social worker. The first author interviewed all the male participants alone and was accompanied by a female practitioner for interviews with female participants. The interviews lasted between 60 and 75 min. All the interviews were audiotaped. Participants were given an identifier, ID1, ID2, etc., to ensure their confidentiality.

The audiotaped interviews were transcribed verbatim to ensure the details of the information. Data analysis followed the three stages set out by Smith and Osborn [25]. Stage 1 involved numerous close readings of the transcripts to acquire familiarity with the content. The first author then read the transcribed data line by line to identify points of interest and significance. In Stage 2, the transcripts were re-read to identify emerging themes and confirmed by the first and second authors, who are qualified sex therapists with bilingual backgrounds. In Stage 3, emergent themes, linking themes, and relevant verbatim quotes were compiled and then grouped into overarching themes and given an appropriate descriptive label in English following discussion between all the authors to achieve consensus.

Results

Table 1 provides general information about the participants, type of daily engagement and living arrangements. Three participants were male, and two were female. They were aged between 21 and less than 50. All had day placements. Two were in open employment in the

catering industry. Two participated in a day activity center and sheltered workshop, respectively. The youngest participant was a student attending a vocational training center, offering a training program specifically for people with disabilities. One participant lived with his parents, and the others lived in supported hostel accommodation provided by a social services agency. Day service centers aim to provide nursing care, rehabilitation, social and personal care services for people with intellectual disabilities; sheltered workshops aim to enhance the working capacity of people with intellectual disabilities to enable them to move on to supported or open employment wherever possible; supported hostels aim to enhance residents' quality of life, maximize their potential, enhance their independent living skills and facilitate their integration into the community. Three participants reported experience of a romantic relationship with a member of the opposite sex.

The themes: understanding and doing

Participants' sources of information about intimate relationships or their sexual behavior were more or less the same as their counterparts without disabilities. For example, participants acquired information from sex education programs offered by teachers or social services staff or their parents. Similarly, they had exchanged information among their peers or searched the internet. Further analysis of the interview data identified two salient variations: "understanding" and "doing".

Understanding

According to Patel et al. [27], adequate comprehension of the sexual situation is a prerequisite for solving problems and making decisions. The level of understanding in that area is influenced by an organized structure of prior knowledge and beliefs. During the interviews, participants discussed their understanding of intimate relationships or sexual behaviors. As Table 2 illustrates, "understanding" comprised three sub-themes: "concepts on intimacy or sexuality", "the 'should' concept on sex" and "misconceptions about sex".

Understanding: concepts on intimate or sexuality

When asked what they had learned from sex education, participants most commonly identified biological knowledge about sex organs or human sex development and the

Table 1 Summary of participants' background

	Sex	Age	Day Placement	Living Condition	Self-reported Romance Relationship
ID1	M	40	Open Market (Western Restaurant)	With Family	One
ID2	F	> 30	Day Activity Centre	Hostel	One
ID3	M	25	Open market (Fast Food Restaurant)	Hostel	None
ID4	F	> 40	Sheltered workshop	Hostel	Three
ID5	M	21	Student in a vocational training centre	Hostel	None

Table 2 Participants' conceptualization of intimate or sexual behavior

Theme	Sub-themes
Understanding	Concept on intimacy or sexuality "Should" concept on sex
Doing	Misconception about sex Intimate or sexual behavior Yes.....but.....

consequences of unprotected sex. ID2 and ID4 mentioned receiving information or discussing sexuality with parents and social services staff:

At school, we had a class about sex. I also learned about it from the internet. I know that making love would make a baby. But I also know that using a condom can help. [ID2]

I wanted to know why a man would put sperm into a woman's body and how it eventually becomes a baby. And why I should have a period. But my mother just smiled and did not answer my question. I asked the female staff and she told me that it was about puberty. [ID4]

Understanding: the "should" concept on sex

Participants also mentioned having been taught how to behave in encounters related to sexuality or romantic relationships. For example, children were asked not to watch scenes involving kisses or cuddles on television or in movies [28]. In this regard, participants' understanding of the situation was classified as "should manner":

It is not ok to see the characters in a movie kissing each other. I cannot fast-forward the movie clip because I live in a hostel. I will go to my room to wait until the scene comes to an end if there is such a scene. [ID4]

When there is a scene on the TV about sex, my parents or my siblings tell me that it is a forbidden scene. [ID5]

This kind of "should manner" is not just about how participants should behave openly but extended to participants' private lives:

I should not think about sex because it is only allowed after marriage. [ID1]

I should not browse any website related to sex even if no people are around me. It is not proper. [ID3]

The "should manner" also demonstrated gender specificity regarding dating and sexual behavior. Both female participants reported that they should comply with their parents' or social services staff rules:

A boy wanted to kiss me. I said no because I was told that I should not do this. And if this is discovered by staff, they would scold me. [ID2]

My mother told me that we should not be touched by any man. Men are no good. They would only take advantage of me. [ID4]

Understanding: misconceptions about sex

Sexual myths are beliefs without scientific value that individuals consider are true in sexual matters and are often exaggerated or false [29]. People are still woefully misinformed about sex. Participants revealed misconceptions about sex:

Semen is related to health. If I lose one drop of semen, I will lose three drops of blood. So, masturbation is not healthy. I want to have sex. But I cannot. If it is outside marriage, I would be in jail. [ID3]

The man wanted to touch me, kiss me. I am afraid of having a baby. It is not ok to have a baby if I am not married. [ID4]

I saw my classmate reading a porn magazine. I wanted to see it too. But sex is dirty. And I know that if I read it, I will be blamed as an insane person. [ID5]

Doing

Participants were invited to talk about their experiences of dating or expressing sexually related behaviors. ID1 mentioned that he had only one experience of hanging out with a girl. The two female participants, ID2 and ID4, mentioned dating three and two men, respectively, preceding their admission to the support hostel. They also discussed the reasons for not maintaining the relationship. The male participants discussed their experiences of masturbation and reading porn material.

Doing: intimate or sexual behavior

Sexual behavior can be understood as physical contact together with a psychological phenomenon. A sexual act is not merely a solitary activity but exists on a continuum ranging from solitary activity, for example, masturbation, to activity with another person, for instance, kissing and hugging. Participants revealed similar sexual expressions and need as their counterparts without disabilities.

A girl was introduced by my parents. I had dinner with her. Afterwards, we hung out at the shopping mall. [ID1]

I felt good to date the boy. I knew him when we were working in the same sheltered workshop. He had kissed me. We had hugged each other when we were in a park or our parents were not at home. [ID2]

I felt happy when a boy said he loved me. We were working in a sheltered workshop. But I did not keep up our relationship because he wanted to touch my body, which I think is no good. [ID4]

Masturbation refers to the practice of stimulating one's own genitalia in such a way as to produce sexual arousal and possibly orgasm [30]. Generally, it is viewed more positively nowadays [31]. Participants also mentioned their experiences of masturbation:

I used my mobile phone to watch a porn video at nighttime after all my roommates are asleep. I usually keep the volume down. It is ok. Nobody would find out. [ID3]

Sometimes I would like to watch porn videos. But I struggle. It seems that masturbation is not a good thing. [ID5]

Although no participant reported having any experience of penetrative sex, some had experienced some kind of sexual contact with another individual:

He touched my body; he kissed me. He also asked me to touch him as well. But I didn't. It is so ugly. [ID2]

He touched my thigh. He wanted to kiss me. I said no. But eventually we separated because he found another girl. [ID4]

Doing: yes..... but

We also asked about participants' feelings about their sexual lives. They said they could go no further in their relationships, primarily because their parents forbade them to have a romantic relationship, but also because social services staff prohibited any behavior related to sex, such as hugging, fondling or kissing. In this regard, therefore, participants' responses comprised a theme of "Yes..... but...." mixed with various types of feeling:

I want to have a family. My brother and sister have families. I feel so envious. But I cannot. I have no money, which is essential for marrying a girl. And my parents said that I should not get married. [ID1]

I felt good when he touched me (coily smile when talking about this). But my father did not like him. Both my parents said that it is not good for me to be in a relationship. But my brothers are. I feel lonely when I see them. [ID2]

The feeling of ejaculation is good. I want to date a girl too. But you know, people would think that I am a crazy guy. I think I should behave. [ID3]

Someone dates you is just so happy. I want to have a relationship. It makes me feel cold and lonely that I have no partner. But I should not do this (sexual act). I would die if staff discover this. The staff here will definitely scold me. [ID4]

It just felt so pleasurable when ejaculated. But I should focus on my studies. Indeed, my parents and staff here do not allow me to have a relationship. And I feel too shy to date a girl. [ID5]

Discussion

Sexual activities and desire are natural aspects of being human [10]. They evoke a kaleidoscope of feelings, including love, excitement, and tenderness and are a key factor associated with overall mental, physical, and emotional health in humans [32]. Sexuality certainly involves knowledge about the human body and social concepts on relationships. It also involves culture, the pattern of values, ideas, and the symbolic system that shapes human behavior [33]. In this regard, society and the family provide the best acculturative arena for socializing and constructing personal goals and values in sexuality [34].

Figure 1 illustrates the results of this study. First, it enabled participants to indicate some sexual knowledge and conceptions (and misconceptions) and recount their experiences of romantic relationships and sexual activities. This can be classified as participants' "knowing" about sexuality. Secondly, it revealed that people with intellectual disabilities have the same desires to have a romantic relationship with another person as those without disabilities. Those "feelings" displayed mixed emotional states towards the unmet need for sexual expression. The study further revealed how participants' sexual expression was controlled and regulated.

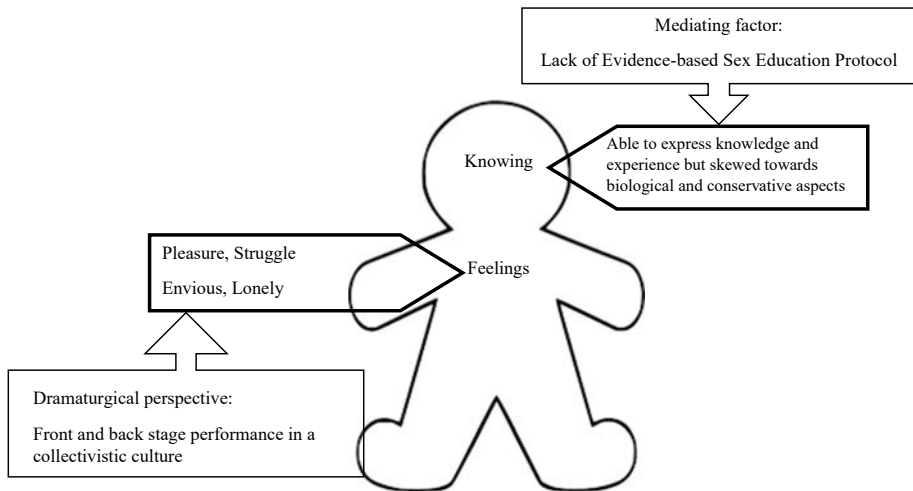


Fig. 1 Pictorial illustration of the sexuality experience of people with intellectual disabilities

Knowing: culture and the education system and their influence on participants' understanding of sex

Sexuality knowledge reported by participants was mainly skewed towards biological information of the reproductive system and reproduction. Regarding relationships or intimate behavior, participants tended to behave in a “should be” manner. They also had some misconceptions about sex. Hong Kong’s sex education system is a potentially influential factor in shaping this situation.

Sex education should be age-appropriate and culturally relevant, teaching sex and relationships by providing scientifically accurate, realistic, and non-judgmental information. With the ultimate goal of improving audiences’ sexual health and overall quality of life, sex education’s mission should extend beyond the transfer of knowledge about human physiology, the reproductive system, or the prevention of sexually transmitted infections and empower the audience better to understand their sexuality and relationships [35]. Policy-makers and professionals in Hong Kong agree on the “one curriculum for all” concept [36]. In essence, learners with and without disabilities should be exposed to and taught the same curriculum with universal aims and instructional objectives to fulfill each learner’s life-long goals in an inclusive community [37]. However, sex education in Hong Kong has not been positive for people with intellectual disabilities. The Family Planning Association of Hong Kong began to promote sex education in the 1960s. In 1986, the Education Department of Hong Kong published a detailed guideline on sex education in secondary schools with recommendations on topics, resources, and references for promoting relevant programs. Subsequently, in 1987, 1990 and 1994, the Advisory Inspectorate of the Education Department conducted three surveys to investigate the implementation of the 1986 Guidelines in schools. The results were somewhat disappointing, with no improvement in the delivery of sex education in Hong Kong schools [38]. The guidelines were revised further in 1997 to strengthen the implementation of sexuality education in schools, but were for reference only [39], and have not been revised since [40]. Consequently, each school is free to choose if and how to implement sex education. Ng [41] commented that the guidelines

were deeply skewed towards moral indoctrination and family relationships, offering limited or basic information only on sexual anatomy and physiology, sexual behavior and psychology. Moreover, they are silent regarding controversial issues like sexual variation, prostitution and pornography. Other studies have also pointed out that the 1997 Guidelines showed a strong bias towards teaching young people socially and morality accepted manners [42]. In addition, there are no evidence-based sex education programs for schools in Hong Kong [40]. Considering this contextual background, it was hard for participants to be taught a well-designed sex education program. Further, these might be potential factors skewing the formation of participants' knowledge and attitudes in biological and conservative directions.

Feeling: dramaturgical perspective on participants' mixed feelings

In addition to knowledge about sex, participants expressed a range of feelings towards their sexuality-related status. When participants were asked about their feeling and desire regarding a relationship, the shared affectionate responses were pleasure and struggle. On the one hand, they expressed enjoying the feeling of being in a relationship or kissing or being touched. On the other hand, participants preferred to keep their parents in the dark about their relationships or sexual activities. Participants recounted that they had kissed or touched their partner in the park, when their parents were not at home or on other occasions when they were not subject to "surveillance" by social services staff. They enjoyed the moment. Participants had the same desire for a relationship as people without a disability, but they struggled with this because their parents and social services staff did not permit them to have a relationship. In addition to feelings of pleasure and struggle, participants also displayed other affectionate responses, envy and loneliness. Participants expressed that they felt envious when they saw siblings having a relationship or even a family. Nevertheless, when they realized that they were prohibited from being in a relationship or expressing sexual desires, the shared response was loneliness. These interwoven feelings (pleasure, struggle, envy and loneliness) can be rephrased as: "I want to..... but I have to....." and the dramaturgical perspective provides a framework to explain this situation.

Dramaturgical perspective: front stage for a Chinese child in a collectivistic culture

Goffman [43] uses the metaphor of drama to outline how individuals become performers, engaging in certain behaviors that attempt to guide and control others' impression of them. An individual plays a part, implicitly seeking others' acceptance and belief in the impression they foster. This role-playing can assume a real dimension for a child such that they may come to see their performance as reality. This is the "sincere" performer, one who is "sincerely" convinced that the impression of reality they stage is the real reality". Goffman also identifies front- and back-stages. The location of a particular performance is the front-stage, where the individual emphasizes those aspects of the performance that are favorable to their definition of the situation and "have to" suppress those aspects that might discredit it.

There could be noteworthy interaction between "onstage" performance and collectivistic cultures. Collectivism is a value characterized by emphasizing group cohesiveness and prioritizing the group [44]. People from collectivistic cultures do not perceive themselves as being alone. Instead, collectivistic cultures shape people to be relational beings who tend to identify as members of their social groups and "have to" comply with the values

and norms of the group to which they belong. Therefore, under the umbrella of a collectivist society, interpersonal connections are strong and substantial [45, 46]. Chinese culture and family life have been described as prototypically collectivist [47] and as strongly influenced by Confucian values [48], emphasizing affiliation, cooperation and harmony in interpersonal relationships. Chinese obligations to their family, and especially filial piety, guide their behavior [49]. Obedience to parents and submitting to parents' demands are highly valued. Thus, Chinese children commonly "have to" subordinate personal values and individualistic goals to the larger group and prioritize social and moral values over individual needs and desires [50]. In the Chinese context, parental expectations of a child extend far beyond having a good education to acquiring a professional or managerial position and achieving an admirable social status [51]. Furthermore, a child's maturity is perceived as family business, a phenomenon indicated by a Chinese proverb, "wang zi cheng long", a wish that the child could become a "dragon"—the symbolically successful and glorious animal in Chinese culture [52].

Under this cultural umbrella, a Chinese child "has to" be on stage to act a performance centered on achievement-based domains such as academic performance or professional achievement [53]. A child's academic achievements are related to developing a desirable social image and preserving respect from others [54]. Therefore, Chinese children commonly want to succeed, feel good, and bring honor to their families. In such circumstances, it should not be a surprise that participants had the belief that they "have to be a good kid".

The converse of saving face is to avoid losing it. "Face" relates to how one thinks about oneself and how one is evaluated by other people whereas losing face is related to losing the family's dignity [55, 56]. Face loss is a major consideration in Chinese relationships and a much stronger predictor of relationship deterioration than in other cultures [57, 58]. First, a parent of a child with intellectual disabilities in a society that places more emphasis on face concern is more likely to internalize feelings of shame, self-blame and powerlessness [59]. Research demonstrates that Chinese families, one of whose members has an intellectual disability, face greater stigma compared with other types of disability [60, 61]. "Courtesy stigma", also referred to as "stigma by association", involves public disapproval as a consequence of association with a stigmatized individual or group [61, 62]. According to Goffman, stigma is a social attribute that discredits an individual or group that could negatively impact self-concept and emotions, in particular shame and guilt. Individuals thus could experience certain levels of social exclusion, such as difficulty engaging in regular social interaction, because of shame resulting from societal discrediting. Second, witnessing behaviors associated with sexuality could be anxiety-provoking. Despite a profound social revolution over the last two decades, many Chinese currently maintain a relatively conservative attitude towards sexuality [63]. The interplay between the dramaturgical perspective and collectivistic culture appears correlated with Asian parents' attitudes. Asian parents' expectations that their child exhibits self-control in their behavior is a highly valued norm [64].

In other words, children in Asian families "have to" behave according to their social group's cultural norms and expectations. People with intellectual disabilities experience challenges being the "dragon"; however, they can behave in a socially accepted manner on the front stage by not talking about sex or showing any behavior associated with sexuality that can embarrass their parents. The study findings reflected this; although participants mentioned feelings of pleasure or envy and loneliness when they yearned for a relationship, they illustrated their compliance to parents' "doctrine" not to have a relationship. Participants also demonstrated their struggle to achieve self-control, inhibit self-interests and personal desires, and control emotions to be a "good behaved Chinese child" [64].

Dramaturgical perspective: Chinese children experience their sexuality on the back stage

According to Goffman [42], everyone consciously or unconsciously plays a role. However, in a desire to offer an idealized presentation, the performer must conceal actions that would otherwise contradict the performance. This strategy of hiding contradictory actions is referred to as “secret consumption”. Although participants demonstrated restrained front-stage behavior, they also reported experiences of sex-associated behaviors.

The back-stage is where rehearsals and preparatory activities occur, where individuals effectively let down their hair. Here they can express feelings and thoughts that would ruin their front-stage performance [65]. For most people, a sexual encounter might be the most intimate and private aspect of their lives. This situation is akin to an actor staying in the back-stage that can reveal the real-self and is free to choose what to wear [66]. Participants mentioned their experiences of kissing and fondling as their counterparts without disabilities. However, the back-stage for people with intellectual disabilities is not exactly the same as that for people without disabilities.

Participants’ opportunity to relax in the back-stage environment without an audience is different from those without disabilities. During the day, participants were in an environment where social services staff provided training or supervision. At night, they were either at home or a hostel under the supervision of parents or social services staff. Participants mentioned their ability to enjoy a private sexual life at night when there was no staff or parental “surveillance” or going to a park where they could be alone.

According to Couwenhoven [67], sexual activity often moves into the public arena when limits or restrictions are placed on private sexual expression. In one study, restrictions placed by family and service providers led people with intellectual disabilities to explore different locations for sexual activity, including parks, back alleys, behind stores, bathhouses, the street, and other public settings [30]. In addition to the restrictions imposed by parents and social service staff, living situations in Hong Kong perhaps play a part in diminishing the back-stage opportunities for people with intellectual disabilities [68]. Rocketing property prices and rents in Hong Kong have aggravated problems of privacy, compromising quality of life [69], and increasing participants’ difficulties in addressing their privacy needs when handling issues relating to sexuality. In Hong Kong, the necessity of living in a shared room with 2–4 people in a supported hostel is a universal practice. The structured and comparatively small rehabilitation environment prevents people with intellectual disabilities from having private contact to explore sexual relationships safely and in a dignified manner. Indeed, such an environment places people with intellectual disabilities under surveillance, making it easier for staff to control their behavior [70].

Implications

Participants demonstrated the ability to describe their knowledge, lived experiences about sexuality and voiced their desires and struggles in a Chinese community. In general, they had limited sexual knowledge and demonstrated some misconceptions. These findings echo previous research on sexuality and intellectual disabilities [71, 72]. Restrictions on participants’ sexual lives were imposed by others, which is also consistent with previous research [1, 73]. As members of a collectivistic culture, participants did not demonstrate significant

resentment of their struggle. This attitude towards the status-quo perhaps creates a cycle: participants were not habituated to looking for increased independence, while parents or social services staff seldom considered the righteousness of relinquishing control over people with intellectual disabilities.

A potentially quick way to enable people with intellectual disabilities to have a relationship to enrich their sexual life experience would involve modification of the physical structure of some service centers, for example, providing private space. However, parents or staff are likely to resist this, particularly in a collectivist culture where sex is taboo. Changing a culture is a profound task that cannot be accomplished in a single move. However, empowerment work is one potential way of helping people with intellectual disabilities increase control of their sexual lives. Some individuals may feel psychologically empowered when they interpret and perceive their lives as meaningful, feel free and competent to determine their lives, and envisage success with a sound impact [74]. Research also reports people with disabilities participating in serious leisure activities enabling them to develop increased levels of confidence, skills and self-esteem [75]. Therefore, although it is not easy to empower people with intellectual disabilities to gain more self-government of their sexuality, we may first consider helping them participate in activities focusing on their strengths to enhance their self-esteem and courage to ask for autonomy.

Moreover, it is essential to provide training and support for caregivers to increase their confidence in dealing with the sexuality of people with intellectual disabilities. Caregivers should also be involved in the formation of intervention programs and even the intervention process, so they receive the same information and experiences as people with intellectual disabilities. This strategy is believed to assist the establishment of the common ground for both parties to communicate, which is significant in the transformation of attitudes [76].

Social stigma and social expectations are believed to influence participants' feelings and the reluctance of their family and social services staff to talk about sex. At the societal level, evidence-based intervention programs, for example, enabling direct contact and familiarity with people with intellectual disabilities, should be promoted [77]. Delgado and colleagues [78] argue that anti-stigma programs should address the more obvious negative reactions towards people with intellectual disabilities and affective reactions associated with compassion and emotions that can perpetuate paternalistic prejudices and the stereotypes of low competence and high sociability. Hence, in addition to the protocol to jointly engage people with and without a disability, multi-media can also play an important role in mitigating stigma and changing societal attitudes towards people with intellectual disabilities, for example, making a YouTube movie to illustrate the capacities of or the life story of a family with a member with intellectual disabilities.

Study limitations

The sample size for this study was small. However, it was very difficult to recruit participants for a face-to-face interview during the pandemic. The cross-sectional and convenience sampling design might influence the understanding of the experience in sexuality among people with intellectual disabilities. The negotiation process between people with intellectual disabilities and their family or social service staff about sexuality is unknown. Future research should address these limitations by employing a prospective cohort design and involve a larger purposive or probability sample to examine in more detail and at multiple time points the process of negotiating autonomy for people with intellectual disabilities.

Conclusion

People with intellectual disabilities share the same human need for affectionate and intimate relationships as those without a disability. People with intellectual disabilities in this study expressed their experiences and needs regarding their sexuality. Although concerns have been expressed, people with intellectual disabilities have the right to exercise personal autonomy. Promoting their rights regarding sexuality issues is a challenging task; however, starting with anti-stigma campaigns probably offers one solution. Priority should be given to help people with intellectual disabilities and their families to regain their rights and self-determination regarding their sexuality. Further research must pay specific attention to the experiences and challenges regarding sexuality faced by people with intellectual disabilities and their families within a specific cultural context.

Funding The authors declare no funding received for this publication.

Declarations

Conflict of interest All the authors declared that they have no conflict of interest.

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Chapter Conclusive Summary

This chapter stated the perspective of people with intellectual disabilities on sexuality and intimate relationship. Same as the ordinary population, people with intellectual disabilities share the same sexual feelings and need. However, in the context of enjoying sexual life, or engaging in intimate relationship, people with intellectual disabilities have faced the barriers that were built by staff and parents.

In the next chapter (chapter 6), the text will present the findings from the perspective of parents with a child with intellectual disabilities, For the chapter 7, the barriers constructed by social services staff will be mentioned.

Chapter Six

Shame: the voices of parent of people with intellectual disabilities about the handling of the sexual need of their child with intellectual disabilities

Chapter overview

This chapter is based on the finding from the group of participants, Chinese parents with a child with intellectual disabilities and focuses on their experience about the handling of the sexual need of their child with intellectual disabilities. sexuality and intimate relationship. Through the interviews, three salient variations in participants' attitudes towards the child's sexual needs: concern, reluctance, and prohibition. Most participants further displayed a layer of feeling that combined "love" and "grief". Stigmatization and collectivist culture is believed to play the role in influencing the parental attitudes, concerns, and beliefs.

Chapter structure

This section is based on a publication (Publication 5) in the British Journal of Learning Disabilities. In the next page, the paper as in the format of the journal article will be presented. Prior to the end of the chapter, a conclusive summary would be provided.

Citation of the paper: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2022). Voices from parents on the sexuality of their child with intellectual disabilities: A socio-emotional perspective in a Chinese context. *British Journal of Learning Disabilities*, <https://doi.org/10.1111/bld.12448>

Voices from parents on the sexuality of their child with intellectual disabilities: A socioemotional perspective in a Chinese context

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Abstract

Background: This qualitative study explored the attitudes and experiences of Hong Kong Chinese parents/carers relating to the sexual needs of their child with intellectual disabilities.

Methods: Semi-structured interviews were conducted in Hong Kong with seven parents/carers applying Interpretative Phenomenological Analysis to explore their experiences of and attitudes towards the sexual needs of their adult child with intellectual disabilities.

Findings: Data revealed three salient variations in participants' attitudes towards the child's sexual needs: concern, reluctance and prohibition. Participants' anxiety about discussing sexuality was evident. Most participants further displayed a layer of feeling that combined 'love' and 'grief'. Based on Goffman's dramaturgical perspective, participants exhibited front stage and back stage behaviours that are believed to be strongly influenced by stigmatisation and collectivist culture.

Conclusion: Various levels of intervention to reduce stigma are identified and discussed. This study also highlighted the role of caring professionals in generating awareness of the cultural impact on the family and the need to carefully address the subtle feelings experienced by family members with intellectual disabilities.

KEYWORDS

empowerment issues, health & social care policy and practice, intellectual disability, parenting, sexuality

Accessible summary

- People with intellectual disabilities experience physical changes and wide-ranging sexual expression. Their parents are among the most important influences on the development of their sexuality.
- This study investigated the experiences and attitudes in Hong Kong of parents/carers with an adult child with intellectual disabilities regarding their child's sexuality.

- We considered what mattered most to parents/carers in three areas: They have had less concern with sexuality, they were hesitant to talk about sex, and were not allowing their adult child with intellectual disabilities to have sex or romantic relationships. Parents/carers were also anxious about discussing sexuality and displayed feelings that combined 'love' and 'grief'.
- Stigma should be reduced. Caring professionals should also be aware of the cultural factors that impact the feelings of people with intellectual disabilities and their parents.

1 | INTRODUCTION

Sexual well-being is a key factor associated with overall mental, physical and emotional health. Young people's sexuality development marks a shift in physical changes in early to middle adolescence, in their relationships with their families and a growing sense of autonomy (Tulloch & Kaufman, 2013). People with intellectual disabilities also experience physical changes and the spectrum of sexual expression; some prefer to abstain from sexual activity, whereas others express a positive sense of engaging in this (Lam et al., 2019). However, research indicates that adults and young people with intellectual disabilities report discussing sexual issues with friends and family less frequently than other young people (Isler, Tas et al., 2009). According to Pownall et al. (2011), they have comparatively limited social networks and autonomy, spending more time under the supervision of adults or caretakers. They often lack opportunities for informal exchange of information with peers, to develop romantic relationships like their nondisabled peers, or even have a social life (Pownall et al., 2011; Vuuren & Adlersey, 2020). In short, the sexual liberty of people with intellectual disabilities is compromised.

1.1 | Parents' attitude on the sexuality of children with intellectual disabilities

Research reveals attitudinal differences between parents and staff, with parents holding more conservative attitudes on sexual expression of people with intellectual disabilities (Chou et al., 2016; Cuskelly & Bryde, 2004; Tamas et al., 2019). Isler, Beytut et al. (2009) reported that parents in their study had not received any formal education on sexuality; some participants reported not talking about sexuality with their children with intellectual disabilities and more than half had a negative opinion about masturbation. In a later study, Pownall et al. (2011) reported that mothers perceived their child with intellectual disabilities to have a continuing dependency and limited opportunities for intimacy offering reasons for them to avoid the subject of sex to talk to their child. More recent research revealed that parents of a child with intellectual disabilities experienced anxiety when discussing their child's emerging sexual behaviour, admitting their difficulty in thinking about the topic (O'Neill et al., 2016). Parents'

conservative and avoidant attitudes are consistent with the recognition of parental prejudice as an obstacle to the empowerment of people with intellectual disabilities to self-determine their sexuality (Lam et al., 2021). This protective and disempowerment attitude is identified as paternalism, which assumes people with disabilities need to be cared for, supported or managed for their best interests, but infringes their freedom and autonomy (Foley, 2017).

1.2 | Chinese parenting attitudes in sexuality

Parents are a powerful source of influence over young people's sexual health through communication, monitoring and surveillance (Deptula et al., 2010). Sexual attitudes within Chinese cultures, however, tend to be more conservative than in non-Chinese cultures (Cheng et al., 2012; Vuuren & Aldersey, 2020). Research has shown that parents and adolescents in China infrequently communicate about sexuality (W. Liu et al., 2015). Moreover, Chinese culture is generally considered collectivistic and thus emphasises the interdependence between people, family and various social organisations, particularly concerning personal face in front of others (Hofstede, 1991; Oh et al., 2014). In line with this, Chinese parents regularly exert a higher level of control over children, encourage conformity within the family and to authority and exhibit more restraint during eating, social play and talking about sex (Keshavarz & Baharudin, 2009; T. Liu et al., 2017; Rudy & Grusec, 2006). The exertion of power reinforces the paternalist care of parents/caregivers and the perception of people with intellectual disabilities as vulnerable.

1.3 | Human attitudes as performance in a social context

Humans are social and emotional beings. Viewed through a social constructivist lens, 'individual' and 'society' are interdependent (Billett, 2006). Attitudes do not emerge as solely personal or individual but arise from interactions with others in the social system (Bidjari, 2011). Moreover, emotions are believed to be the responses of the environment and mediated by cognitive processes that provide meaning or value to social cues (Fox, 2015). Thus, human attitudes and feelings are context-dependent and responsive to factors within a particular sociocultural environment.

Further, according to Goffman (1972), people everywhere are taught to be perceptive and to seek the approval or respect of others; they typically desire the approbation of the social group to which they belong. People's behaviour is a theatrical performance that is more about a person's feelings about their image as seen through the eyes of others, the person's social group, community or a wider public (Goffman, 1959, 1972). When a person sees their own image in this social 'mirror' constituted by others, their emotional state will inevitably be affected by the vision their imagination presents and will be involved in the processes of feeling pride, embarrassment or whatever state through which the individual's face is formed and responds to (Qi, 2011). As Goffman (1972) stated, a person tends to experience an immediate emotional response to the face that contact with others allows. Performance in front of others, therefore, is not to be detached or separated from emotion; rather, face is infused with different emotions and exists in terms of them.

Qualitative research allows individuals to respond to their own categorisation and perceived associations to the understanding of the perspective of others, for example, parents on sexuality issues relating to their child with intellectual disabilities. By considering the local organisational culture and interrelated processes of personal experiences, attitudes, and practices, to formulate an 'emic' perspective (Arboleda-Flórez & Stuart, 2012; Ungar et al., 2016), this paper describes the findings of a qualitative study that explored Chinese parents' attitudes towards the sexual needs of their child with intellectual disabilities.

2 | METHODS

2.1 | Design

A qualitative approach using semi-structured interviews based on Interpretative Phenomenological Analysis (IPA; Smith, 2004) was chosen because of its particular efficacy in researching sensitive topics by providing participants with the time and space to express their idea(s) and concerns in their own terms. IPA explores the meaning and sense-making of a phenomenon amongst a well-defined sample (Smith & Osborn, 2008). The theoretical origins of IPA reside in phenomenology, ideography and hermeneutics, focussing on experience, the particular and interpretation (Smith et al., 2009). In practice, IPA facilitates exploration of participants' experience of their world through the analysis of data from small, homogenous samples, acknowledging the active role of the researcher in the interpretation of these experiences (Smith & Osborn, 2008). The sexual development of a young person during the transition to adulthood may encapsulate parents' fears and may provide particular concerns for parents of people with intellectual disabilities (Pownall et al., 2011). IPA was considered appropriate for this study because the goal was to establish the meaning of parents' views in the context of their family lives, emotionally laden life-transforming events and broader social circumstances (Neergaard et al., 2009; Smith, 2004).

TABLE 1 Characteristics of participants and their child with intellectual disability

Parent/carer	Relationship to child	Child	Age of child	Services received	Child's functional level described by parent/carer
P1	Mother	2 Sons	30	Half-time support worker	Both independent in ADL, and able to travel independently daily to work place
			20	Working for the family business	
P2	Mother	Son	18	Final year at special school	Independent in ADL, commuting independently daily between home and school
P3	Father	Son	24	Sheltered workshop	Independent in ADL, commuting independently daily between home and workshop
P4	Aunt	Niece	32	Hostel and sheltered workshop	Independent in ADL, able to cook a meal, commuting independently daily between home and workshop
P5	Mother	Son	32	Part-timer courier	Independent in ADL, able to travel to different places independently to deliver packages
P6	Mother	Son	35	Day activity centre	Independent in ADL, commuting independently daily between home and centre
P7	Mother	Son	33	Sheltered workshop	Independent in ADL, able to cook a meal, commuting independently daily between home and workshop

Abbreviation: ADL, activity of daily living.

2.2 | Ethics and interviews

Approval for the study was given by Tung Wah Colleges Research Ethics Committee (REC2019049) as a low-risk proposal. A purposive sample of six Hong Kong Chinese parents with at least one child aged over 18 years with mild intellectual disabilities and a woman who acted as the carer for her adult niece with mild intellectual disabilities was recruited. Social workers in a parent resource centre in Hong Kong sent invitations to participate in the study, all of whom provided their informed consent. Participants were interviewed regarding their views and experiences in handling sexuality issues relating to their child. Semi-structured interviews were used, with open-ended questions that allowed space for participants to express views and feelings and relate experiences that may have been unique to them. The interview schedule was influenced by Bevan's (2014) proposal that a phenomenological interview should cover three key elements: contextualisation, apprehending and clarifying the phenomenon. Interviews took between 55 and 80 min. Participants were identified as P1, P2 and so forth to ensure confidentiality. After the interview, participants were given a local supermarket voucher as a token of appreciation, approximately equivalent in value to GBP£10.00. Participants' demographic details are shown in Table 1.

2.3 | Analysis

All interviews were audiotaped and transcribed verbatim. The three stages of data analysis set out by Smith and Osborn (2008) were employed. Stage 1 comprised numerous close readings of the transcripts to acquire familiarity with the interview content. The first author then read the transcribed data line by line to identify points of interest and significance. In Stage 2, the transcripts were reread to identify emerging themes and confirmed by the first and second authors, who are qualified sex therapists. In Stage 3, a set of emergent themes and relevant verbatim quotes was compiled; all linking themes were then grouped into overarching themes and given a descriptive label in English by the first and second authors, who are bilingual. These themes were finally endorsed by all four authors.

3 | RESULTS

Five participants were mothers, one a father and one the child's aunt and primary carer since the child's birth. One 18-year old attended a special school; the others were over 20 years old and took part in various daily activities, including attendance at a day activity centre and employment in the open job market. Participants reported that all the adult children were independently able to undertake daily living activities and travel to their school or workplace. In other words, at the time of the interview, no participant was required to provide intensive daily care for the child.

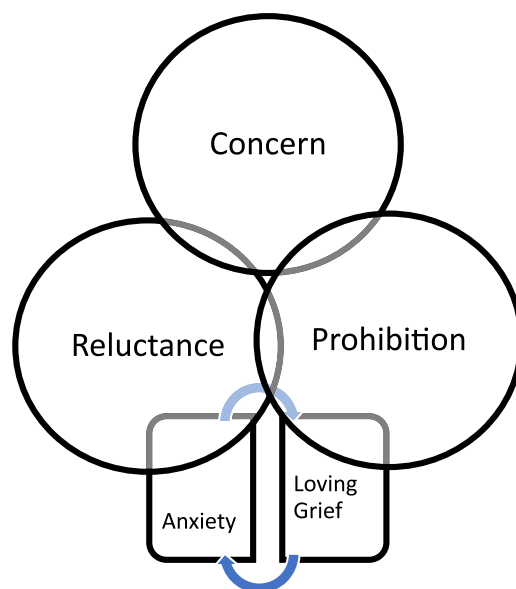


FIGURE 1 Pictorial representation of the three themes and the attached feelings

During the interviews, no participant mentioned that their child was in any type of romantic or sexual relationship. But it was not uncommon to notice participants' acknowledgement of sex as a normal and basic human need. One mother stated that she recognised that everyone has sexual desires and so did her son. Another parent also agreed that it is right and normal for anyone to go on a date. In-depth dialogue about the child's sexually-related behaviour identified three salient variations in participants' attitudes towards the child's sexual needs: concern, reluctance and prohibition (Figure 1).

The most common response relating to the theme 'concern' was 'sex is not the priority, I have a long list of concerns like self-care, basic community living skills...' (P1). The second theme, 'reluctance' was evidenced in comments like, 'I know my son has sexual needs, but I am hesitant to talk about this' (P5). And the third is 'Prohibition' which was revealed in the later part of the interview when participants were provided with the hypothetical scenario of their child with intellectual disabilities having a romantic relationship or getting married, and engaging in a normal sexual life, with one parent expressing, 'Sorry, I don't accept this' (P6). Furthermore, at some point in the conversation about the second and third themes, participants also revealed having two tiers of feelings, anxiety and loving grief (Figure 1).

3.1 | Theme 1: Concern

Although participants recognised that sex is a basic human need, they shared their opinions that sexual education was not a priority for their children's training or learning. The participants were concerned that a child with intellectual disabilities should spend more time

acquiring daily living skills or vocational tasks, specifically in self-care and preparation for employment:

At different stages, we have various kinds of concern. For example, in the early stage, we had to focus on self-care training. Later, we were concerned about vocational training. Those are my priority concerns and they made me exhausted already. (P6)

In addition, some participants believed that sex education should have been covered in the special school curriculum and that further training on this was unnecessary.

I think my boy has learned that (sex education) from school already. Therefore, I think I can be excused from talking about this. (P2)

Except for P2, whose son still attended a special school, all participants' children were adults and engaged in regular day-time services, such as attending a sheltered workshop or having a job in the open market. No participant expressed concern about the child's performance of daily living tasks, or undertaking basic household tasks. No participant intended to initiate any discussion, training or education activity related to their child's sexual needs or facilitate a romantic relationship. If a situation arose requiring participants to discuss sexual issues with their child, the focus of discussion was mainly on self-protection, or not touching their sex organ in the presence of other people to avoid embarrassment.

3.2 | Theme 2: Reluctance

Sex can be a sensitive and awkward topic that raises feelings of embarrassment. Parents may experience discomfort and ambivalence about when, what, and how much to say to their child regarding sexuality (Elliott, 2010). Some participants expressed their preference to not talk about sex with the child:

I would not talk about this (sex). If my kids do not ask me any questions about this (sex), I prefer not to raise this topic by myself. (P1)

If you ask me to talk to him on what sex is, what could I do? ... If he asks me more in-depth about this (sex), it will be a bit embarrassing. (P3)

Participants mentioned their experience of facing situations in which their child expressed sexualised action/behaviour, for example, touching their genitalia or watching a sex-related video. Parents' assumption of their child's abstention from sexuality was recurrent in subtle ways; some stopped the child's behaviour immediately while others preferred to ignore it:

It is dirty (masturbation). Do it in the toilet! (P3)

I knew he wet his pants. But... I would not like to check it out. What if I confirmed that it is? ... Do you know what I mean? I would rather ask my husband to handle this issue. (P5)

In addition to participants' overt verbal responses, their emotions were also observed. Participants appeared to be at ease at the beginning of the interview, although when the discussion included the child's sexual behaviour, for example, the discovery of the child masturbating in their bedroom, or discussion of the participants' attitudes towards sexual matters, they appeared to be anxious and exhibited fidgety reactions; for instance, an inability to sit still, rubbing their fingers and tightening their shoulders. Participants also admitted that sex was not a topic for discussion even with their spouse:

I would not talk about sex personally with my husband, but he (husband) does. Maybe I am conservative. I would not like to talk about this topic. (P6)

3.3 | Theme 3: Prohibition

Apart from the experiences encountered by participants, the researchers found that providing a context with 'who' and 'what' helped facilitate participants' expression of their thoughts and enrich the depth of discussion. Participants were provided with a hypothetical scenario about their child having an opportunity to engage in a romantic relationship involving sexual activities or marriage. Participants responded that they would use various kinds of 'reasons' to dismiss requests from their child with intellectual disabilities to develop any kind of romantic relationship. For example, one of the parents (P3) told his son that a romantic relationship could only be allowed at the age of 50. Furthermore, participants perceived their child would have no capacity to understand the real and complicated meaning of a relationship or marriage. In addition, some participants displayed 'stereotyping' attitudes that no one would wish to engage in a relationship with a person with intellectual disabilities. Simply put, under this theme, participants affirmed that they would see this more as a threat than an opportunity through their explicit repression of sexual relationships and activity beyond masturbation:

I don't think he is smart enough to understand the meaning of marriage. And I would feel a bit embarrassed to discuss this topic with him. My bottom line is that he can go to the toilet to 'do it' (masturbation). Anything beyond that, I do not think is appropriate. (P3)

If he says 'I want to get married', I would rather be dead. What if he had a baby? It would be just another pain for us. It would be impossible for his child to have a chance to have upward mobility. I know I am taking away some kind of life experience from him. But I have to. (P1)

Participants' anxiety about discussing sexuality was evident. In-depth analysis of the interviews revealed that most participants displayed another layer of feeling that combined 'love' and 'grief'. On the one hand, participants mentioned that the love they gave to their child was the best:

I know he really wants to have a girlfriend. But I cannot accept that. Indeed, I do not believe there is anyone who would love my boy more than me. (P6)

I am his mum, I would take care of him forever. Indeed, who would give real love to my boy? (P7)

Beyond never-ending love and caring, on the other hand, participants also revealed their grief of being the parent of a child with intellectual disabilities and terminating this 'disability journey', in which parents' determination to end the journey indicates pessimism and disappointment regarding a personal and family 'tragedy'.

If they really think about marriage and sex, it may result in them having children. It is so sad. Why go to the trouble of having another disabled generation? (P1)

It is very painful to have a child with intellectual disabilities. Marriage for him? I think that the story should end here. (P5)

4 | DISCUSSION

This study explored the views of parents/carers about sexuality issues of an adult child with intellectual disabilities, as well as about their child forming intimate relationships. Participants displayed three different types of view regarding their child's sexuality: concern, reluctance and prohibition. Two tiers of feeling, anxiety and loving grief, interweaved the lines of participants' dialogues. The dramaturgical perspective (Goffman, 1959) provides a potentially appropriate sociological model to explain this phenomenon. According to Goffman, people engaged in social interactions aim to avoid being embarrassed or embarrassing others. Goffman creates a theatrical metaphor, defining human beings presenting themselves to others based on cultural values, norms and beliefs, and as a connection between the kinds of acts that people perform in their daily lives as a theatrical performance (Goffman, 1959). There is a front region that individuals perceive themselves as an actor on the front stage in a theatre. The region emphasises desired impressions, for instance, how to apply make-up and what to wear in front of the audience. Conversely,

there is also a back region that is typically out of bounds to members of the audience. A region does not require the use of curtains. The actors can reveal truths and is free to choose what to wear or set aside their role (Ritzer, 2011).

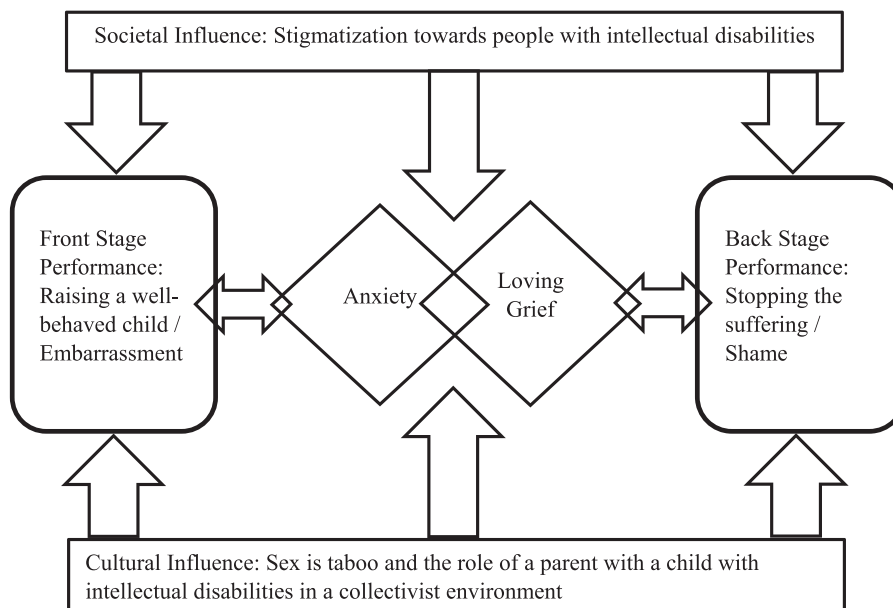
Human beings are wired to be social (Castiello et al., 2010). Human emotions have inherent social components and can be viewed as tending to be elicited by others, expressed towards others and regulated to influence others (Gilovich et al., 2019; Kleef, 2009). The social world is not merely something that exists external to the individual but internalised from their early years (Schneider et al., 2012). In the context of a dramaturgical world, people's performance is not to be detached or separated from emotion (Goffman, 1972). The social emotions of embarrassment and shame are fundamentally to do with self-presentation (Sabini et al., 2001). Embarrassment arises when individuals reveal an apparent flaw of the self in front of others, for instance, in making a faux pas (Eller et al., 2011). However, even when the audience is not explicit shame is still thought to originate from social sources and is elicited when individuals evoke an image of a disapproving 'imagined other' who negatively evaluates the self (Dickerson et al., 2004).

As illustrated in Figure 2, the performance of study participants on the front stage is about how they raise a child with intellectual disabilities. In this daily life presentation, participants indicated their concern about the performance of their child in front of other people. At the personal level, this type of concern is highly correlated to feelings of anxiety, a psychobiological response, and eventually leads to embarrassment, a social-emotional response (Eller et al., 2011; Hemm et al., 2018). At the back stage of this dramaturgical environment, parents can step back from the influence of anxiety that allows them to disclose their inward affective response: loving grief. This back stage affective response should be evaluated together with the social emotion, shame, a key and innermost affective response to a social-evaluative threat (Dickerson et al., 2004; Vuuren & Aldersey, 2020). In addition, the stigmatised social environment and the collectivist cultural atmosphere are believed to be the two indispensable components that influence the emergence of the front stage and back stage performance of study participants.

4.1 | Front stage: Impression management and avoidance of embarrassment

In this study, the front stage is regarded as the participants' performance for impression management about raising a child with intellectual disabilities. According to the dramaturgical perspective, people are 'onstage' in front of their audience and perform as expected by their culture, even when they are not fully self-aware that they are performing. Since human beings are social animals, people tend to behave or 'perform' based on the social norms in the presence of others (Aronson, 2018; Hegtvædt & Johnson, 2018). This tendency is called self-presentation theory or impression management, the way an individual adjusts the self to gain social influence and acceptance by managing the impressions made on others (Heinzen & Goodfriend, 2019). P6 provided a good illustration of this: 'I am the type of parent that cares about the expectations of my son'.

FIGURE 2 The entanglement between parents' feeling and the social world regarding the sexuality of children with intellectual disabilities



In a social situation, people can be actors or observers. To take an actor perspective, people are more likely to adopt embarrassment-avoidance responses (Li, Drolet et al., 2018). When discussing sexuality issues with their child with intellectual disabilities, participants were potentially observed as actors. During the interviews, participants were observed to experience anxiety when talking about sexuality issues. They expressed feeling ashamed when dealing with their child's sexual-related behaviour and showed the avoidance attitude if their child touched or hugged someone, despite the possibility of this simply being an exhibition of the child's basic need for affection. The embarrassment-avoidance response is illustrated by P7: 'It is so embarrassing if my son tries to hug someone. The best way to handle this is to deal with it at the beginning by not allowing him to do it'.

Dialogue on sexuality could be anxiety-provoking. Despite a profound social revolution over the last two decades, many Chinese maintain a relatively conservative attitude towards sexuality (Woo et al., 2011), and therefore not much has changed over this time-frame (Higgins et al., 2002). Although Hong Kong is considered the 'Asiatic World City' and the most westernised Chinese society due to its heritage as a former British colony, in contrast to its international city peers, sexuality is not as openly discussed or expressed and remains something of a taboo (Andres et al., 2021). To act socially accepted on the front stage, participants clearly stated that they seldom talked about sex with their partners to avoid feelings of embarrassment. In addition, Chinese people often talk about it in an ambivalent way or tend to use 'code' to disguise sex organs and sex-related activity (Lei, 2016). Study participants consistently attempted to camouflaging sex-related terms by using 'it' to refer to the penis or vagina and the very vague phrase 'he was doing that thing' instead of the explicit term 'masturbation'.

There could be noteworthy interaction between the 'onstage' performance and collectivistic cultures. Collectivism is a value characterised by emphasising group cohesiveness and prioritising the group (Gilovich et al., 2019). People from collectivistic cultures tend to identify as members of their social groups and are driven by the values and norms of

the group they belong to (Hofstede, 1991; Triandis, 1995). Apart from the importance of cohesive social groups, Asian groups tend to have greater concern for 'loss of face' (dignity) and disruption of group harmony compared to other ethnocultural groups (Lui & Rollock, 2018). Thus, people from a collectivistic background have been taught to exercise self-control, inhibit self-interests and personal desires and control emotions from a young age to reduce the chance of 'losing face' of the family and disturbing others (Li, Vazsonyi et al., 2018; Vuuren & Aldersey, 2020). The interplay between the dramaturgical perspective and collectivistic culture appears to be correlated with Asian parents' attitudes. Asian parents' expectations that their child with and without disabilities exhibit self-control in their behaviour is a highly valued norm (Li, Vazsonyi et al., 2018). In this study, the discussion of nurturing a child with intellectual disabilities revealed a pattern in line with that interplay. Study participants focused on the performance of the child with intellectual disabilities in daily living tasks. In addition, the child should not do anything sexually or embarrassing in front of other people. P4's response regarding her niece provides a relevant example:

My idea is to provide training for my 'daughter' on self-care, cooking, and obtain vocational training and a hostel place for her. If there is a scene related to kissing or hugging on TV, I would ask her to look away and tell her that it is forbidden. (P4)

4.2 | Back stage: Scripts highlighted by shame, an innermost social emotion

In addition to the front stage, people engage in back stage behaviour, to let down their guard and reveal their feelings shown by their uninhibited true selves (Hegtvædt & Johnson, 2018). Consistent with the notion of front stage performance, participants living in a collectivistic society showed their concern about their child's behaviour in

front of other people. Thus, they made great efforts to raise a well-behaved child. However, a sense of helplessness and hopelessness emerged when participants talked about their experience of being a parent of a child with intellectual disabilities, described their experience as 'suffering'. As one parent emphasised, 'the story should be stopped here'.

One feeling participants revealed was 'loving grief', an ambivalent emotional state. On the one hand, participants declared their love for their child. On the other, they referred to raising a child with intellectual disabilities as 'suffering' and the loss of the 'normal' development trajectory experienced by other parents, for example, their child's marriage, having grandchildren and being supported in old age by their child. In short, participants named it as a 'suffering' that they did not want to perpetuate.

This kind of suffering is not simply a personal perception; it is also a confluence of personal feelings and contextual pressure. Parental goals and values are influenced by the social context and factors such as culture and individual experience. The family is the best acculturative arena for socialising and constructing these goals and values (Ren & Edwards, 2015). Furthermore, the family is a social unit in society and the space for socialisation and upbringing (Aronson, 2018). Parents are expected to enjoy seeing their child growing as an independent and autonomous individual. Any changes or development of a child can be regarded as a reward for the efforts of parenthood. These changes lead to maturity, in particular, to parenthood, a socialised process that most people, including parents themselves, believe is one of the most important components that fulfil the lives of individuals (Gilovich et al., 2019). However, there is a persistent negative perception, particularly in Asia, that people with intellectual disabilities are incapable of achieving these normative trajectories (Vuuren & Aldersey, 2020). For parents of a child with intellectual disabilities, the journey of raising that child perhaps is a trail of bitterness. Riemann and Schutze (1992) point out that the trajectory of being a parent of a child with intellectual disabilities initially possibly throws the parents into a state of shock, passivity, and even sometimes into a state of paralysis, especially when it comes to organising everyday activities. In the mid-stage of the trajectory, parents might discover some new potential to change their child's status, but this could result in further disappointment when they find their child is unable to achieve subsequent psychophysical and social development milestones (Riemann & Schutze, 1992), and discover that the parent-self is unable to enjoy the 'harvest time' when children mature and reciprocate (Gilovich et al., 2019). This new version of 'otherness' could lead to a breakdown in expectations in common discourses of life events that they were used to.

The uncritical, strong notion of independence of this normal developmental trajectory interacting with the perception of people with disabilities as dependent and vulnerable, resulted in 'pain' and 'suffering' as these parents could not connect with the social norm (Huang et al., 2020). They appeared to be experiencing constant grief as departing from the social norm, and their narration often included phrases such as 'always' or 'for the rest of my life' when discussing the future.

Parental expectations can be regarded as values or targets they have about their child's future performance that are mainly centred on achievement-based domains such as academic performance or professional achievement (Barber & Rao, 2005). In the Chinese context, parental expectations of a child extend far beyond having a good education to acquiring a professional or managerial position and achieving an admirable social status as a child's maturity is perceived as family business (Zou et al., 2013). This phenomenon is indicated by a Chinese proverb, 'wang zi cheng long', a wish that the child could become a 'dragon'—the symbolically successful and glorious animal in Chinese culture (L. Liu & Wang, 2015). To assess this phenomenon specifically in the Hong Kong context, Shek and Chan (1998) revealed that parents projected that an ideal child should fulfil family responsibilities as well as the uncriticized strong notion of independence, such as having a good relationship with their parents, a positive attitude towards studying and good academic achievements. In addition, parents in Hong Kong expect their child to be mature, of good character, self-disciplined outside the home, obey the law, not associate with undesirable peers or misbehave (Ang, 2006). A participant echoed these expectations of independence clearly and showed her disappointment: 'Every parent hopes their children will have a bright future. I admit that I am that type of person... But in reality, my son cannot do it' (P6). This perception of people with intellectual disabilities as interdependent and vulnerable is rooted in society.

Suffering can be regarded as deep personal anguish that is correlated with stigma (Yang, 2015). Research demonstrates that Chinese families with a member with intellectual disabilities encounter higher stigmatisation compared with other types of disability (Huang et al., 2020; C. S. Lam et al., 2006; Vuuren & Aldersey, 2020). Stigma discredits an individual or group and exerts a negative impact on self-concept and emotions, in particular shame and guilt (Goffman, 1963). Parents of a child with intellectual disabilities thus could experience certain degrees of social exclusion, such as difficulty engaging in normal social interaction and trajectory, because of shame resulting from societal discrediting. Consistent with this, participants did not perceive their child having a sexual life or getting married as positive; rather, they perceived this as an extension of their suffering and attracting more shame that is always hovering at the back of their minds at the back stage, and contrasts with the front stage performance of loving their child and trying their best to teach them to be a well-behaved person. As a result, paternalism is reinforced 'choicelessly' to continue the front stage decent 'performance' and thus reduce the possibility of shame.

Stigma and shame not only emerge from the perceived interdependence and vulnerability of people with intellectual disabilities but also Chinese culture. Chinese culture is characterised by interdependence, whereas having a family member with disabilities is an interwoven set of interactions interplaying at the back stage. Shame, defined in terms of an interpersonal orientation in which behaviour is compared to social norms (Lam et al., 2006), is the common social emotion among Chinese families with a member with disabilities due to social stigma, social expectations and face concerns (Chiu et al., 2015; Yang, 2015). In the context of front stage performance, embarrassment is evoked when a person avoids a public social faux pas (Goffman, 1959; Shulman, 2017). Congruent with the concept of back stage, on the other

hand, shame is both an artefact and a powerful inner emotion holding those parents in bondage, isolating them and altering their world view. Consequently, collectivists are concerned about their social faces when the actual or imaginary presence of an audience is not necessary to galvanise feelings of shame in the back stage milieu. Shame is thus one of the most damaging consequences that potentially immerses participants in negative self-evaluation and further internalises shaming thoughts; hence the actual presence of others is not always necessary (Henriksen & Mesel, 2021; Yang, 2015). This self-internalisation, again, manifests a vicious cycle by the perception of people with intellectual disabilities as 'captives of care', and further intense paternalism and less autonomy.

4.3 | Implications for practice

In sum, stigmatising attitudes in collectivist cultures create a stressful living environment for families with a member with intellectual disabilities (Hua et al., 2019; Ran et al., 2021). Although further training for people with intellectual disabilities perhaps a way to enhance their 'front stage performance', the perceptual change in parents/caregivers are more important. It is crucial to remove the reluctance and prohibiting attitude from parents. With this, people with intellectual disabilities are believed to have more opportunities to access the training on relationships and sexual education. In addition, as illustrated in the study, this stigmatised social world engulfs the esteem of a family with a member with intellectual disabilities. On the back stage, even without an audience, the intertwined feelings of anxiety, loving grief anchored to social taboos on sexuality further mediate the esteem of the family with a child with intellectual disabilities. To reduce stigma at the family level become more essential. Practitioners should empower the family by interventions to enhance family acceptance of the child with intellectual disabilities as a capable, contributing member of society (Vuuren & Adlersey, 2020). In addition, caring professions should increase awareness of the cultural impact on the family and carefully address the subtle feelings experienced by family members (Govere & Govere, 2016).

Social stigma and social expectation are believed to have a role in the formation of feelings of shame. At the societal level, evidence-based intervention programmes, for example, with direct contact and familiarity with people with intellectual disabilities, should be promoted (Werner, 2017). Delgado et al. (2018) argue that anti-stigma programmes should not only address the more obvious negative reactions towards people with intellectual disabilities. They should also address affective reactions associated with compassion, as these emotions can perpetuate paternalistic prejudices and the stereotypes of low competence and high sociability. Hence, in addition to the traditional protocol such as activities that jointly engage people with and without a disability, multimedia can also play an important role in mitigating stigma and changing societal attitudes towards people with intellectual disabilities (Maulik et al., 2017, 2019). In this regard, perhaps, YouTube's videos may be a good channel to illustrate the true capacity of people with intellectual disabilities or the life story of a family with a member with intellectual disabilities.

4.4 | Limitations

This study had several limitations. All participants were recruited through a parent resource centre in Hong Kong whose experience in the back region may differ from parents receiving different services, and experiences may vary according to the experience of social services and community linkages. Another key limitation is gender and role disproportionality. Only one father participated in the study, thus limiting the views from fathers. Further exploration of fathers' experiences is necessary to broaden the conceptualisation on handling sexuality issues among families with a child with intellectual disabilities. Lastly, although the first author is an experienced counsellor and sex therapist, and consciously used gender-neutral language to talk about sexuality and intimacy, in the context of Chinese communities, female participants may have felt uneasy and inhibited sharing their thoughts with a male interviewer.

5 | CONCLUSION

People with intellectual disabilities share the same human need for affectionate and intimate relationships as those without a disability. Promoting the rights of people with intellectual disabilities on sexuality issues is a challenging task, but priority should be given to help them and their family members to regain their rights and self-determination regarding their sexuality. Based on the study, parental attitudes towards the sexuality of people with intellectual disabilities are a complex phenomenon intertwined with social, emotional and cultural factors. Services provided by practitioners and further research that pays specific attention to people with intellectual disabilities and their family experiences and challenges in sexuality within a cultural context are particularly essential.

CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

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How to cite this article: Lam, A., Yau, M. K., Franklin, R. C., & Leggat, P. A. (2022). Voices from parents on the sexuality of their child with intellectual disabilities: A socioemotional perspective in a Chinese context. *British Journal of Learning Disabilities*, 1–11. <https://doi.org/10.1111/bld.12448>

Chapter Conclusive Summary

This is the second chapter to present the findings of this doctoral study. Parents with a child with intellectual disabilities were interviewed. Their perspectives, concerns and related emotions were reported. Same as the findings in chapter 5 and 7, Chinese culture is believed to be the key factor to influence the findings.

In the previous chapter (chapter 5), the text presented the findings from the perspective of people with intellectual disabilities on sexuality and intimate relationship. In the next chapter (chapter 7), the barriers constructed by social services staff will be mentioned.

Chapter Seven

Challenge: barriers faced by social services staff in the handling of sexuality of people with intellectual disabilities

Chapter overview

This chapter comprises the data collected from social services staff working for people with intellectual disabilities. All the participants supported people with disabilities to have the right to enjoy their sexual life. However, they faced different barriers in that area when attempts were made to actualise such belief. In the context of supporting the sexuality of people with intellectual disabilities, this chapter employed the cultural perspective to explain the actions and responses carried by social services staff. Implication to social services, and recommendation to future research are also discussed.

Chapter structure

This section is based on a publication (Publication 5) in the Journal of Applied Research in Intellectual Disabilities. In the next page, the open accessed paper will be presented as in the format of the journal article. Subsequently, a chapter conclusive summary would be provided.

Citation of the paper: Lam, Y.K.A., Yau, K.S.M., Frankie, R., Leggat, P. (2022). Challenges in the Delivery of Sex Education for People with Intellectual Disabilities: A Chinese cultural-contextual analysis. *Journal of Applied Research in Intellectual Disabilities*.
<https://doi.org/10.1111/jar.13025>

ORIGINAL ARTICLE



Challenges in the delivery of sex education for people with intellectual disabilities: A Chinese cultural-contextual analysis

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Abstract

Background: Staff members' views can have a significant impact on sexuality issues of people with intellectual disabilities. Research on the impact of sociocultural factors in this area in the Chinese context is sparse.

Methods: Semi-structured interviews were conducted with seven professionals (social worker, nurse, life skills trainer and manager) to explore their experiences of and attitudes towards the sexual needs of people with intellectual disabilities by applying interpretative phenomenological analysis.

Results: The study identified two major themes, each with two sub-themes: 1. Professional handling of the sexual needs of people with intellectual disabilities (sex education and intervention); 2. Barriers (incompatible approaches and parental resistance). Participants also experienced feelings of resignation facing the barriers they encountered. Collectivism and cultural view about sex are potentially the influencing factors.

Conclusion: This study highlights the need to adopt an evidence-based sex education programme whose content and delivery should take account of cultural factors.

KEYWORDS

Chinese culture, helping professions, Hong Kong, people with intellectual disabilities, sexuality

1 | INTRODUCTION

People with intellectual disabilities have the same sexual needs and desires as people without disabilities (Young et al., 2012). They also experience similar physical changes and the spectrum of sexual expression; some prefer to abstain from sex, whereas others express a desire and need to engage in a romantic relationship and sexual activity (Lam et al., 2019). Research reveals that people with intellectual disabilities lack opportunities for an informal exchange of information with peers, or even a social life, and the opportunity to develop romantic relationships like their peers without a disability (Isler et al., 2009; Pownall et al., 2011). According to Pownall et al. (2011), people with intellectual disabilities have a comparatively limited social

network and autonomy, experiencing more time under the supervision of family members or caretakers.

Although research suggests that helping professionals, such as social workers, nurses or workshop trainers, tend to have moderately liberal or even positive attitudes towards the sexuality of people with intellectual disabilities (Bazzo et al., 2007; Lafferty et al., 2012; Meaney-Tavares & Gavidia-Payne, 2012), other research reveals the controversial nature of sexuality issues (Bernert & Ogletree, 2013; Grieve et al., 2008; Rohleder, 2010). According to a review paper, the prejudices of staff and parents have been consistently identified as obstacles to empowering people with intellectual disabilities to establish their sexuality (Lam et al., 2020). Helping professionals do not proactively initiate conversations about sexuality

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(Abbott & Howarth, 2007; Wilson & Frawley, 2016) or are unprepared to deal with sexual issues (Howard-Barr et al., 2005; Thompson et al., 2014). Some do not feel comfortable talking about sex without proper reference materials because they do not know how to start conversations with people with intellectual disabilities. In addition, the generalisation of skills to real-life situations in sex education for people with intellectual disabilities is often not achieved (Schaafsma et al., 2015).

Sex is considered culturally taboo in Chinese society (Cheng et al., 2012; Kennedy & Gorzalka, 2002). In Hong Kong, despite being an international city, education and training programmes have not progressed from this tendency to challenge sexual prejudice and discrimination against minority groups (Chia & Barrow, 2016). The proposed Anti-Discrimination Ordinance regarding sexual orientation, gender identity and intersex status remains to be enacted because of strong opposition from religious organisations and parent and teacher groups (Kwok & Joseph, 2015), who argue that non-heterosexuality violates religious, moral and Chinese Confucian family values (Kwok, 2019). Religious and parental influences render Hong Kong unfavourable for reducing sexual prejudice against minority groups (Kwok, 2018). Discussion about sexuality in Hong Kong is dominated by dominant societal expectations of heterosexual marriage and a focus on the importance of having children to ensure the care of elders and the continuance of family lineage (Yu et al., 2011). People with intellectual disabilities may legally marry in Hong Kong, unless their mental incapacity is demonstrated. However, parents of people with intellectual disabilities are reluctant to consent their marriage or have offspring (Lam et al., 2022).

From a social constructivist perspective, 'individual' and 'society' are interdependent (Billett, 2006). Thus, attitudes do not emerge as solely personal or individual, but from interactions with others in the historical context and social system (Eiser, 1994). Human emotions are also considered the responses to the sociocultural environment and mediated by individual cognitive processes that provide meaning or value to social cues (Fox, 2015). Therefore, applying the emic approach to investigate local organisational culture and the interrelated process of personal experience, attitudes and practice in social services may enhance understanding of helping professionals' handling the sexuality of people with intellectual disabilities (Arboleda-Flórez & Stuart, 2012; Scarduzio, 2017; Ungar et al., 2016). This article reports the findings of a qualitative exploration of how helping professionals in Hong Kong deliver sex education for people with intellectual disabilities and the sociocultural factors that may impact their attitudes and service delivery.

2 | METHODOLOGY

Based on interpretative phenomenological analysis (IPA), a qualitative approach using semi-structured interviews (Smith, 2004) was chosen. IPA has its theoretical origins in phenomenology, idiography and hermeneutics and focuses on experience, the particular and interpretation (Smith et al., 2009). Smith and Osborn (2008) note that formulating a schedule leads IPA researchers to explicitly consider what they expect the interview to cover and identify any potential difficulties they may encounter regarding question-wording or sensitive

topics. A key advantage of using IPA in this study is that it allowed the researchers to examine and interpret participants' unique understanding of their role and experiences in addressing the sexual needs of people with intellectual disabilities.

The interview approach chosen for constructing the schedule was funnelling (Noon, 2018). This technique is particularly important for this study. Even in a healthcare setting, talking about sex can be a sensitive and awkward topic generating embarrassment among practitioners (Ollivier et al., 2019). Funnelling is a technique that enhances memory recall by starting with broad questions, for example: 'Would you please tell me your duty in working with people with intellectual disabilities?'; 'In general, have you experienced any difficulties in your daily work?' Subsequently, the interview develops a more specific line of questioning related to the experience of handling the sexual needs of people with intellectual disabilities. For instance: 'What specific tasks in sex education or dealing with sexuality have you delivered to people with intellectual disabilities?'; 'Have you encountered any difficulties when you were trying to tackle this issue?'; 'How did you feel when you experienced this type of difficulty?' This approach enabled the authors to glean a more holistic understanding of participants' experiences in dealing with the sexual needs of people with intellectual disabilities.

The study received approval from the College's Research Ethics Committee (REC2019049). A purposive sample of seven helping professionals employed by three different NGOs was recruited. The selection criteria was any level of staff working with adults (age ≥ 18) with intellectual disabilities in Hong Kong who had worked in this field for at least 3 years. The first author invited four NGOs to participate in the study, and three agreed to do so. All participants consented to an interview about their experiences of handling sexuality issues in their day-to-day work. The interviews were held in the workplace's interview or conference room and lasted from 55 to 70 min, and all were audiotaped. Each participant was given an anonymised designation, S1, S2, and so forth, to maintain confidentiality.

The audiotaped interviews were transcribed verbatim to preserve the details of the information. A three-stage approach set out by Smith and Osborn (2008) was employed for data analysis. Stage 1 covered numerous close readings of the transcripts to acquire familiarity with the interview content. The first author then read the transcribed data line by line to identify points of interest and significance. In Stage 2, the transcripts were re-read to identify emerging themes and confirmed by the first and second authors. In Stage 3, a set of emergent and linking themes and supporting verbatim quotes was compiled. All authors reached consensus to group these into overarching themes and provide an appropriate descriptive label in English.

3 | RESULTS

Table 1 provides general information about participants, their work experience and the nature of their current employment. Four female and three male staff, an assistant trainer, trainers, social workers, a nurse and a sheltered workshop manager, participated in the study. Three participants had more than 10 years of experience working

TABLE 1 Background of participants

Staff	Sex	Post	Number of years of experience working with people with intellectual disabilities	Services nature	General job description
S1	Female	Assistant Trainer	5	Day services centre	1. Assist professional staff to implement/monitor rehabilitation progress of service users. 2. Provide daily life skills training for community living on both individual or group basis
S2	Female	Social worker	4	Day services centre	1. Care plan design and counselling work for both people with intellectual disabilities and parents
S3	Female	Manager	>20	Sheltered workshop	1. Workshop management and staff training
S4	Male	Social worker	>10	Sheltered workshop	1. Design and implement vocational rehabilitation plan, connecting employers, and provide training for frontline staff
S5	Male	Nurse	>15	Day services centre	1. Nursing care and medication management
S6	Male	Trainer	4	Supported Hostel	1. Assist professional staff to design/implement/monitor rehabilitation progress of service users.
S7	Female	Trainer	4	Supported Hostel	2. Provide daily life skills training on both individual or group basis

with people with intellectual disabilities, and the others had 4–5 years of work experience. All participants received their education and professional training in Hong Kong, but none claimed any formal sex therapy or sex education training. Five participants worked in daycare and two in residential services. The nature of these services varied and included: day service centres providing nursing care, rehabilitation, social and personal care services for people with intellectual disabilities; sheltered workshops that aimed to enhance the working capacity of people with intellectual disabilities to enable them to transfer to supported or open employment, wherever possible, and supported hostels that aimed to enhance residents' quality of life, maximise their potential, enhance their independent living skills and facilitate their integration into the community.

All participants acknowledged sex as a normal and basic human need and that everyone, including people with intellectual disabilities, desires intimate relationships. Participants shared their experience of knowing people with intellectual disabilities who expressed their wish to have a romantic relationship, for example, with a trainee in the sheltered workshop or a roommate in the same hostel. S2 mentioned that it was common to hear people with mild intellectual disabilities sharing their need for an intimate relationship:

I work in a hostel. My service users saying 'I love my housemate.....', or 'When I see her, I want to kiss or hug....., or I want to have a baby with him' and so forth (S2).

The interviews further explored two major themes (Table 2). First, handling the sexual needs of people with intellectual disabilities, in

TABLE 2 Themes related to handling the sexual needs of people with intellectual disabilities

	Major themes	
	Handling	Barrier
Sub-themes	Sex education	Incompatible approaches
	Intervention	Parental resistance

which two approaches were found: sex education and intervention. Sex education was about helping people with intellectual disabilities gain necessary information and skills about sexuality and socially desirable attitudes. Intervention related to how participants have intervened the situations where people with intellectual disabilities exhibited sexual behaviour or engaged in a romantic relationship. The second theme related to the barriers participants faced in addressing the sexual needs of people with intellectual disabilities. Two salient sub-themes were identified within this theme, incompatibilities among the working team in handling the sexual needs of people with intellectual disabilities and parental resistance in granting more autonomy to people with intellectual disabilities regarding sexuality. In discussing the second theme, participants generally displayed feelings of resignation.

3.1 | Handling the sexual needs of people with intellectual disabilities: Sex education

Providing sex education for people with intellectual disabilities is not uncommon in the services in Hong Kong. However, a prevalent

feature was the focus on biological knowledge related to sex, for instance, the anatomy of the reproductive system and biological responses related to sexual desire between genders. In this study, except teaching physiological knowledge, the delivery of sex education was skewed towards moral indoctrination that people with intellectual disabilities should control their need for intimacy and sexual desire. For instance, parental consent is required for dating. Males with intellectual disabilities were taught to maintain social distance when greeting a girl and touching or kissing only if the girl and her parents consented. Sex education for females with intellectual disabilities more-or-less focused on self-protection. Training seldom addressed issues like same-sex relationships, soliciting sexual services or accessing erotic media or websites. As regards the content of sex education, some participants referred to PowerPoint or other material designed by the Family Planning Association of Hong Kong (FPAHK), a local public statutory organisation that advocates, promotes and provides information, education, medical and counselling services in sexual and reproductive health for the community. Others said that they searched for relevant information on the Internet. All participants considered using sex toys or showing sexually explicit pictures or videos in training sessions inappropriate. Two participants supported such claims:

If two people with intellectual disabilities are in a romantic relationship, I will talk about safe sex. But I will emphasise the criteria for marriage, such as independence in self-care, money management, household work and most importantly, getting consent from parents. (S2).

Talking about sex workers, for example, where would we find a sex worker or the money to pay for their services? Sorry, it is too complicated. It has to involve getting consent from parents. It may require support from the police, and indeed, it may embarrass senior management. I don't think that I should cross this line. (S4).

3.2 | Handling the sexual need of people with intellectual disabilities: Intervention

Participants' intervention to sexualised behaviour or romantic relationships involving a person with intellectual disabilities tended to be gender-specific. For males, the most common sexual expression in the presence of other people was masturbation. Most participants reported either demanding immediate cessation or instructing the individual to go to the washroom. Contrarily, participants rarely reported females exhibiting overtly sexualised behaviour in public. However, when participants became aware of a female service user was in or intending to have a romantic relationship, their common intervention was to teach self-protection and 'say no' skills and inform the woman's parents, a response not commonly found regarding girls without intellectual disabilities in the school environment.

3.3 | Barriers in addressing the sexual needs of people with intellectual disabilities: Incompatible approaches

Most participants experienced a distinct lack of collaboration among different professionals or across different echelons in their work environment towards handling sexualised behaviour of people with intellectual disabilities. For example, according to S1, senior staff, such as social worker or centre manager, were unlikely to accept frontline workers' opinions:

I thought I can handle some situations (challenging sexual behaviour expressed by people with intellectual disabilities), but we have to wait for the approval of senior staff. However, they (senior staff) would frequently say that we need more time to think about the plan..... (S1).

In contrast, another participant thought that the strategies adopted by frontline staff were overly conservative, for example:

Frontline staff often prefer to prohibit any sexualised behaviour or expressions by clients with intellectual disabilities. Some colleagues (frontline staff) would say that allowing people with intellectual disabilities to masturbate, or access any erotic media, is to allow any fallacious ideas and behaviours to rampage arbitrarily in the centre (S5).

Such conflicts do not seem to benefit the welfare of people with intellectual disabilities in the context of facilitating their right to enjoy a similar sex life to that enjoyed by people without intellectual disabilities. However, when asked whether there had been any resolution to this type of conflict among team members, no participant mentioned taking any action to negotiate with their colleagues to achieve resolution.

3.4 | Barriers in addressing the sexual needs of with intellectual disabilities: Parental resistance

Although parents tended to be the most important and consistent influences on a person with intellectual disabilities, their views seem incongruent with those of social services staff who often viewed parents' opinions or attitudes as barriers to providing sex education or counselling:

... in most situations, we have to consult with parents. I would not like to say all, but most parents are conservative in that area (sex). They would prefer that we offered training that simply focuses on vocational or self-care skills. That would be fine for them. (S4).

S3, a middle manager, emphasised the primacy of parents' wishes: 'no matter what [the parents of people with intellectual disabilities] say, we have to follow them', a view echoed by another participant:

The final decision to allow people with intellectual disabilities to have a romantic relationship lies in the hands of parents, even if their view is different from [the person with intellectual disabilities]. (S6).

Parents have a dual responsibility to empower and protect the rights of people with intellectual disabilities in matters related to sexuality (Lam et al., 2019). However, resistance in handling the sexual needs of people with intellectual disabilities does not conform to this image. Instead, parental resistance constrained participants' practice and created a certain level of frustration in the work context.

3.5 | Feelings of resignation

In providing sexuality education and counselling for people with intellectual disabilities, participants expressed feelings of resignation in their daily practice. S7 mentioned agency policy, and most parents' conservatism regarding sexuality. Furthermore, despite incompatibility with her personal values, she was obliged to comply with parents' expectations and agency policy as a staff member. A participant working in a sheltered workshop expressed his feelings of defeat and inability to bring about change:

Even though I would like to talk to those parents, I have never had the experience that senior management would allow us to do anything beyond our existing practice in delivering sex education or addressing sexual issues. (S4).

Another participant who worked in vocational training echoed this view:

We are in a predicament in our work on sex education and counselling for people with intellectual disabilities that it is difficult to get out of. I have worked in this field for over 15 years. The needs of people with intellectual disabilities are always overridden by agency policy, hostel rules, and other restrictions. (S5).

The overall goal of social service provision is to enhance the wellbeing of people within their social contexts, broad professional practice ranging from focusing on individual needs to collective arrangements and social processes that influence the wellbeing of groups (Barnes & Hugman, 2002). However, the delivery of sex education for people with intellectual disabilities or other actions regarding their sexual needs does not reflect this type of approach.

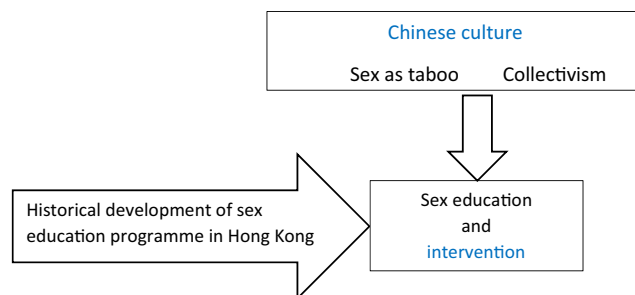


FIGURE 1 Conceptual framework of the influence of historical and cultural factors on the handling of sexual need of people with intellectual disabilities

4 | DISCUSSION

This study explored the views of participants who worked in various disciplines and echelons in social services agencies in Hong Kong on sexuality issues of people with intellectual disabilities. It revealed strategies participants had taken in designing and delivering sex education or otherwise handling the sexual needs of people with intellectual disabilities. It also elucidated the difficulties they faced that impacted their work and their thoughts about those barriers. The common response of participants to these barriers was resignation. Culture was believed to be the mediating factor. The discussion of sexuality or provision of sex education is controversial when it encroaches on cultural territory. Culture is the symbolic system shaping human behaviour (Ho, 2007). In other words, the values embedded in culture create dynamism; simultaneously, culture influences behaviour, while behaviour shapes culture and the distinctiveness of different groups. Figure 1 illustrates a possible relationship between contextual and cultural factors concerning sex education undertaken by participants and their response to barriers. From a longitudinal perspective, the historical development of sex education (curricula) in Hong Kong has created a context that alters the content of sex education designed by the participants. From a top-down perspective, the cultural factor refers to the umbrella of Chinese attitude about sex and the customs and values about relationships; sex is a taboo and a social philosophy derived from Confucianism that people should submit to the social hierarchy and individuals afford lower priority to personal desires where these conflict with the needs of the social group (Taormina, 2014). Consequently, talking about sex is a taboo, and collectivism emphasises social harmony, which acts as a habitual mind set influencing participants' responses to the barriers found in their working environment.

5 | SEX AND CULTURE: INFLUENCE ON THE DEVELOPMENT OF SEX EDUCATION IN HONG KONG

Despite a profound social revolution over the last two decades, many Chinese retain a relatively conservative and suppressive attitude

towards sexuality (Fan et al., 2017; Miles-Johnson & Wang, 2018). Chinese people are bound by traditional values that sex is a private issue, a cultural taboo, a reproductive function, and an act with social and moral ramifications (Liu, 2012). Hong Kong is considered 'Asia's world city' and the most westernised of Chinese societies (Chu, 2011). However, in contrast to its international peers, sexuality is not as openly discussed or expressed in Hong Kong and remains taboo (Andres et al., 2021; Leung & Lin, 2019). According to Jacobs (2009), Hong Kong is a metropolis with a booming sex market offering services such as love hotels, online sex workers and dating services, but sex talk has not proliferated here comparing to the developed countries.

Sex education should be age-appropriate and culturally relevant, teaching about sex and human relationships by providing scientifically accurate, realistic and non-judgmental information (UNESCO, 2009). It should not be limited to the transfer of knowledge on human physiology, the reproductive system or the prevention of sexually transmitted infections. Instead, it should empower its beneficiaries to better understand their sexuality and relationships, ultimately improving their sexual health and overall quality of life (Federal Centre for Health Education [BZgA] & World Health Organization Regional Office for Europe, 2010).

In Hong Kong, under the sex culture as aforementioned, the development of sex education seems not to follow the rationale advocated by UNESCO and WHO. FPAHK began to promote sex education in Hong Kong in the 1960s. In 1986, the Hong Kong Education Department published detailed guidance on sex education in secondary schools with recommendations on topics, resources and references for promoting relevant programmes. Subsequently, in 1987, 1990 and 1994, the Education Department's Advisory Inspectorate conducted three surveys investigating the implementation of the 1986 Guidelines in schools. The results were disappointing, revealing no improvement in sex education in schools (Fok, 2005). The guideline was revised further in 1997, but as an advisory document only (Leung et al., 2019) and has not been revised subsequently (Cheng, 2018). Thus, each school is free to choose if and how to implement sex education. Ng (1998) commented that the guidelines were deeply skewed towards moral indoctrination and family relationships, offering limited information on sexual anatomy and physiology, sexual behaviour or psychology. Nevertheless, discussion on issues like sexual orientation, prostitution and erotic media is limited or entirely omitted. Other studies have also pointed out that the 1997 guideline was strongly biased towards teaching young people socially accepted morality, while discourses on emotional wellbeing and human relationships were largely confined to aspects of human sexuality (Ho & Tsang, 2002). Most schools claimed that sex education was delivered to some grades, but not to the entire school (Cheng, 2018). Moreover, sex education is often an ungraded subject in the syllabus. Thus, in the examination-oriented environment of Hong Kong (Zhan et al., 2013), sex education is usually regarded as of lesser importance (Fok, 2005).

Sexual practices in Hong Kong have come under both traditional Chinese and Judeo-Christian influence (Tsang, 2010). According to

Fok (2005), schools with a religious background were more restrictive in selecting topics for sex education, especially when related to homosexuality and abortion. In addition, both traditional Chinese and Judeo-Christian systems are characterised by patriarchy. This overarching discursive structure dominates individuals' social life about love and marriage by incorporating sex as sexualised and eroticised (Rocha, 2010). In other words, talking about sex is effectively a marriage discourse in Hong Kong as the concepts of sex and marriage are intertwined. The influence of this discourse is reflected in the mindset of parents of people with intellectual disabilities. Lam et al.'s research (Lam et al., 2022) reveals that parents of people with intellectual disabilities believe that any romantic relationship their child has will end in having sex, marriage and even having children. They were anxious about discussing sexuality and prohibited any opportunity for their child to develop a romantic relationship.

There is consensus among policymakers and frontline practitioners in Hong Kong on the 'one curriculum for all' concept (Lian et al., 2007). In essence, learners with and without disabilities should be exposed to and taught the same curriculum with universal aims and instructional objectives to fulfil each learner's life-long goals in an inclusive community. In other words, the same framework of sex education in Hong Kong applies to both the mainstream curriculum and people with intellectual disabilities. People with intellectual disabilities are no different regarding receiving sex education (Schaafsma et al., 2015). However, the sex education delivered by participants in this study was skewed to the provision of biological information within an orientation of moral indoctrination. Given this context, young people with and without disabilities have been taught the same previously-criticised sex education protocol that is biased towards a matrimonial and reproductive discourse. This situation created a dilemma for the study participants and people with intellectual disabilities. In other words, participants taught matrimonially-orientated sex education to people with intellectual disabilities, which is hardly favourable to them because of their limited opportunities for getting married.

As mentioned above, although all participants acknowledged sex as a normal and basic human need and that everyone desires to have intimate relationships, including people with intellectual disabilities, this was not reflected in how participants addressed the sexual needs of people with intellectual disabilities. As sex remains taboo in Hong Kong, the social context of growing up and living environments could impact participants' attitudes, knowledge and skills related to sexuality. All participants received their education and professional training in Hong Kong. Although the study did not investigate participants' attitudes to sex, as a species, humans are social beings who live out their lives in the company of other humans. People organise themselves into various kinds of social groupings in which they work, trade, and play in many other ways. From a social constructivist perspective, a human being is a member of a social beings and codependent with the customs of a society (Billett, 2006). A personal attitude does not emerge as independent from the social context but arises from the exchange of ideas and experiences with others in the social world (Eiser, 1994). In addition, sexual socialisation also takes place outside

the home. Children and adolescents observe community norms, consume mass media, and participate in educational, cultural and religious activities (Shtarkshall et al., 2007). This contextual background perhaps explains participants' rationale for addressing the sexual needs of people with intellectual disabilities. First, the lack of an evidence-based programme on sex education for schools in Hong Kong (Leung et al., 2019) made it difficult for participants to find a suitable reference or formulate their own teaching and learning materials (Schaafsma et al., 2015). Secondly, the contextual background helps explain that actions related to sex education are linked to the heterosexual and matrimonial discourse to a certain extent. The heterosexual discourse ensures that sex education portrays strict gender roles attributed to male and female bodies and social behaviour, for example, that males should initiate dating. The matrimonial discourse emphasises teaching people with intellectual disabilities sexual morality anchored in the ideology of procreative sex and marriage, in which discussion of sexual intercourse is a sub-topic of marriage. Most tertiary education institutions in Hong Kong remain wary of the creative presentation of sexually explicit materials as part of media pedagogy (Jacobs, 2009). Living, growing up and being educated in this kind of social environment, on the one hand, creates the emic perspective of the idea of what a sex education programme should be. On the other hand, participants found difficulty finding a reference or model to deliver their work on sex education. As a result, being members of Hong Kong society, it would be difficult for the participants to act as outsiders or even be 'outlandish' and stand outside the local moral codes to establish a diversified sex education programme. Participant S7 echoed this view: 'we should not do our job in sexuality apart from our norm. We should consider how other people think about the content of sex education'.

5.1 | Collectivist culture: The influence on people's responses to organisational barriers

Chinese culture's emphasis on relationships is another factor that potentially influences how participants delivered sex education and their responses to the barriers they faced. The study revealed conflict and inconsistency between participants and their colleagues in addressing the sexual needs of people with intellectual disabilities. Discussion among team members is essential to resolve such incompatibilities. However, there was no pressing agenda from the management to resolve these conflicts, and participants found dialogue on sexuality could be anxiety-provoking. Hence, despite conflict between team members in dealing with service users' sexuality issues, compromise seems to offer the possibility of ensuring harmony in the workplace to avoid dialogue and conflict on a sensitive topic.

In addition to cultural constraints on talking about sex, Chinese culture plays a potential part in influencing participants' responses to the barriers they found. Chinese is a 'guanxi' culture. Literally, the Chinese term 'guanxi' means 'connections' or 'relationships'. The indigenous *guanxi* culture in China is rooted in Confucianism. It describes personal and non-work-related connections that are

implicitly reinforced by reciprocity and the exchange of favours (Chen et al., 2013). Given that 'guanxi' is an influential philosophy deeply rooted in Chinese society, it is difficult to imagine its absence in Chinese workplaces (Chen et al., 2013; Warner, 2013).

In the human world, conflict exists in all kinds of institutions. People in collectivist cultures prefer a tight-knit social framework in which individuals can expect their relatives, clans or other in-group individuals to look after them in exchange for absolute loyalty (Hofstede, 1991). Individualists handle divergent views expeditiously through open debate or discussion, while collectivists view this as a negative experience to be avoided (Ho, 2007). Some research has also established a relationship between particular cultural values and conflict management behaviour. In general, people from a Chinese background use more conflict avoidance because they value conformity and in-group harmony, while individualists prefer to use more autonomy as they value self-achievement. Research shows that British welfare service executives use more competition and collaboration than their Chinese counterparts, who use compromise and avoidance more (Ho, 2007). Hong Kong remained under British rule for over 150 years. This influence may have resulted in Hong Kong people being less collectivist. However, research refutes this; a study on humanitarian attitudes and support of government responsibility for social welfare revealed that social work graduates in Hong Kong were more collectivist in orientation than their counterparts in Mainland China (Tam, 2003).

From a theoretical perspective (Triandis, 2001; Triandis & Suh, 2002), four types of Individual-Collectivist culture orientations can be identified: (1) Horizontal Individualism (HI-uniqueness), where people strive to be unique and do their own thing; (2) Vertical Individualism (VI-achievement oriented), where people want to do their own thing and strive to be the best; (3) Horizontal Collectivism (HC-cooperativeness), where people merge with their in-groups and (4) Vertical Collectivism (VC-dutifulness), where people submit to the authority of the in-group and for whom they are willing to sacrifice themselves.

Study participants' acceptance of and response to incompatible approaches and parental resistance can be regarded as responses to the influence of horizontal collectivism. Individuals embedded in horizontal collectivism emphasise connectedness, common goals and similarities (Bobbio & Sarri, 2009). Therefore, even though participants recognised incompatibility in their work, none mentioned taking, or willingness to take, any action to resolve such conflict. Any action taken may imply potential criticism of the opinions of team members. While parents of people with intellectual disabilities comprise one stakeholder group, they are not the management in the organisations. Participants may treat the parents of people with intellectual disabilities as in-group members also. One participant said he treated parents as stakeholders: 'I am a father as well. I understand the concern to protect a child, particularly when the child has disabilities'. Every coin has a flip side; although participants would like to go further than they are doing on sex education or addressing the sexual needs of people with intellectual disabilities in a comparatively liberal way, they were aware of the parents' strong resistance. Therefore, they expressed feelings of resignation because of the 'need' to comply

with parents' expectations and agency policy. Central to this state of resignation is a sense of self-defeat and the inability to effect change. However, all participants suffered their resignation 'in silence' when dealing with service users' parents.

Participants' feelings of resignation were also related to the agency management style, where a state of Vertical Collectivism was observed. Participants expressed their dissatisfaction of management, often articulating concerns about the agency's hypocritical approach to sex education that gave lip service to liberal ideals but did not support pluralist sex education in practice. This discrepancy between social welfare practice and agency arrangements regarding sexuality deprived people with intellectual disabilities of a sexual life. Furthermore, it contradicts the notion of social services as a helping profession in its broad contextualised approach to addressing human needs (Barnes & Hugman, 2002).

Although participants' resignation regarding the implicit double standards of senior management was evident, one participant said: 'it is not necessary to do anything beyond the cultural norm and to embarrass the senior management' (S4). This type of 'Vertical Collectivism' response to the conflict is a pattern in which individuals consider themselves members of a group who have different statuses and are willing to sacrifice their personal interests to preserve in-group integrity (Dickson et al., 2003). Therefore, even though participants would like to promote empowerment to address the sexual needs of people with intellectual disabilities, it is apparent that they eventually submitted to the power of senior management.

6 | IMPLICATIONS

This study found that helping professionals in Hong Kong may compromise their autonomy in implementing sex education because of historical and cultural factors. The absence of any mandatory evidence-based sexuality education programme in Hong Kong implies a need for formulating a holistic, replicable and sustainable sex education protocol, the establishment of which could empower people with intellectual disabilities and their trusted adults to build a supportive environment promoting sexual health. The protocol can also construct a learning network to generate longitudinal evidence for the effectiveness of a comprehensive sex education programme to enrich sexual health outcomes. Formulating a systematic and validated training programme for teachers and allied health professionals on sex education is also essential. The programme content should encompass knowledge and skills, attitudes, and values in human sexuality, considering specific cultural contexts.

Culture plays a crucial role in influencing the delivery of sex education for people with and without disabilities. Changing a culture is a profound task that cannot be accomplished in a single move. The government and social service agency leaders should lead in bringing about this change. The task should cover the assessment of needs and concerns in sex education, based on the tripartite perspectives of people with intellectual disabilities, their parents and staff. It is expected that this empowerment work will lead to an open culture where all voices

can be heard without fear of criticism or challenge, which is particularly crucial in discussing sex as an anxiety-provoking subject.

7 | LIMITATIONS

This study has some limitations that should be taken into consideration when interpreting the findings. The sample size was small. However, it was very difficult to recruit participants for a face-to-face interview during the COVID-19 pandemic. The interviews did not explore the actual content of sex education programmes; therefore, other factors possibly constrained the sex education protocol. Participants mainly worked in social welfare service settings; their views could not represent individuals working in other settings, such as special education or healthcare settings. In addition, neither senior management nor government officials participated in the study; therefore, the study does not represent their perspectives. Further empirical research paying specific attention to the attitudes towards sex of senior management and government officials would help promote a holistic service that addresses the sexual needs of people with intellectual disabilities. Examination of the interaction between these parties would also enrich our knowledge and inform practitioners about the development of sex education programmes.

8 | CONCLUSION

In conclusion, endorsement from government and social services agency leadership is essential for adopting an evidence-based sex education protocol, particularly for people with intellectual disabilities. Future research and evaluation should focus on improving understanding of health care practitioners' attitudes towards sexuality and their competence in delivering sex education and training for people with intellectual disabilities. The aim is to enrich the understanding of the contextual environment of people with intellectual disabilities. Hopefully, these suggestions will empower people with intellectual disabilities to enjoy positive relationships and experience good sexual health and wellbeing.

ACKNOWLEDGEMENT

Open access publishing facilitated by James Cook University, as part of the Wiley - James Cook University agreement via the Council of Australian University Librarians.

FUNDING INFORMATION

The authors received no financial support for the research, authorship and/or publication of this article.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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How to cite this article: Lam, A., Yau, M. K., Franklin, R. C., & Leggat, P. A. (2022). Challenges in the delivery of sex education for people with intellectual disabilities: A Chinese cultural-contextual analysis. *Journal of Applied Research in Intellectual Disabilities*, 1–10. <https://doi.org/10.1111/jar.13025>

Chapter Conclusive Summary

This chapter illustrated the perspective from social services staff on the sexuality of people with intellectual disabilities. Their actions for handling the sexual need of people with intellectual disabilities and related barriers faced were discussed in detail. The sex culture in Hong Kong, under Chinese environment, were believed to play a role in influencing the works of the social services staff.

The study employs the pluralistic approach combining the application of Interpretative Phenomenological Analysis (IPA) and Dramaturgy analysis. Based on these two theoretical frameworks, the next chapter (chapter 8) will present the analysis on the tripartite dynamic on the sexuality issues of people with intellectual disabilities within the Chinese socio-cultural context. The insights gained from the findings will also be described.

Chapter Eight

Theatre: front stage performance of the tripartite troupe

Chapter overview

This thesis has revealed hitherto the findings collected from three groups of participants: people with intellectual disabilities, parents of people with intellectual disabilities, and social service staff working for people with intellectual disabilities. The findings covered the knowledge and attitude of participants sexuality. The first part of this chapter will explain how cultural factors influence participants' understanding of sexuality. Subsequently, this chapter will provide a unique perspective to explain the underneath feelings of the participants to the circumstances related to the findings. Based on dramaturgical perspective as a theoretical underpinning, the latter part of this chapter will give a detailed analysis on how Chinese socio-cultural environment influences the tripartite group dynamic on the handling of the sexuality of people with intellectual disabilities..

Sex Culture

Sexuality covers a broad and complex terrain involving sexual identities, beliefs, behaviours, perspectives, practices, and social organization. Filled with cultural meanings, these elements compose a unique framework for understanding sexuality (Agocha, 2014). The following section will give a quick glance on sex culture of Chinese. Afterwards, the influence of sex culture on the knowledge and attitude of the participants of this study will be discussed.

Chinese Sex Culture

Chinese culture is comparatively conservative in sexuality (Zheng et al., 2011). Decades of quantitative and qualitative evidence has demonstrated that East Asian sexuality differs significantly from western norms on dimensions, ranging from accuracy of sexual knowledge to sexual experience, and sexual attitudes (Woo et al., 2010). For example, East Asian individuals were found to have lower acceptability of same-sex oriented sexual activity, casual sex, non-traditional gender roles, and extramarital sex, when compared to their Caucasian peers in Canada (Meston et al., 1998). In the comparison between East Asian and mainstream university students in the United States, background of the participants and acculturation together were the factors that has influenced on the establishment of conservative values in sexuality (Leiblum et al., 2003; Brotto et al., 2005; Ahrold & Meston, 2010). Further, East Asian university females were found to score higher, not only on endorsement of sexual conservatism beliefs, but also on beliefs about sexual pleasure being sinful, and procreation was the main goal of sex (Morton & Gorzalka, 2013).

From a qualitative perspective, Hong Kong Chinese have had a rigid definition of sexual behaviour: confining sex to heterosexual sexual intercourse, while not to consider kissing, hugging, and caressing as 'sexual'. (Yan, et al., 2011). Moreover, Chinese viewed sex and other expressions of romance and personal interests as shameful (Zheng et al., 2011). A more recent qualitative study (Dang et al., 2017) examined the narratives and experience of sexual desire of Chinese. Participants expressed the pressure to hide or inhibit their sexual desire to avoid social condemnation. Last but not least, gender inequality still exists. Research found that the maintenance of male power has suppressed sexuality and limited opportunity for women in society (Jeffreys, 2015).

Changes in sexual morals and practices do not happen in isolation. Indeed, it is important to locate sexuality in wider social, cultural, economic, and political contexts (Jackson and Ho, 2014). The Chinese cultural understanding of sexuality is a complex intertwinement of traditional and modern attitudes. Confucianism represents one of the dominant moral philosophies that has shaped Chinese culture through much of its history. Regardless, Neo-Confucian philosophy during the Song Dynasty (960-1276 CE) has promoted a sexually restrictive doctrine, with strict moral and social codes (Bond, 1991). These included the prohibition of sexual activity except for reproduction within a marriage and condemnation towards overt expressions of sexuality (Gao et al., 2012). Similarly, the “Yin-Yang” doctrine of health saw activities including masturbation and same-sex intercourse, particularly among men, as unhealthy and dangerous (Ng & Lau, 1990). Women traditionally were prescribed to be housebound and submissive (Higgins et al., 2002) and were judged on the bases of chastity, fertility, and housekeeping ability, and were expected to be devoted to their fathers, husbands, and sons (Berdahl & Moon, 2013).

Restrictive attitudes towards sexuality continued when the People’s Republic of China (PRC) was founded in 1949. Open discussion on sexuality was seen as shameful, counter-revolutionary, and symbols of the bourgeois class (Evans, 1995). During the Cultural Revolution, the Communist state expected men and women to be fully devoted to revolutionary ideals while the need on romantic love or sexuality should be put aside. Official government publications often warned of the dangers and immorality of homosexuality, extramarital sex, and prostitution. Although this period led to abolishing arranged marriages and emerging of egalitarian roles for women in Chinese society, other important issues, such as women’s sexual health and gender equality in society were often not substantively addressed (Higgins et al., 2002). Even though some positive changes associated to marriage and equality were

established, sex and sexuality were still controlled under conservative social norms (Cheng et al., 2012; Kennedy & Gorzalka, 2002).

Sex Culture in Hong Kong

One of the dominant ideological frameworks of western culture, Christianity, frequently describes sexual desires as sinful and corrupt but emphasized celibacy as the ideal (Runkel, 1998). Hong Kong, as a British colony for over 150 years and is considered “Asia’s world city”, it is not difficult to find the imprint of the biblical theology of sex in the local scene (Chu, 2011). In contrast to its international peers, sexuality is not as openly discussed or expressed in Hong Kong (Leung & Lin, 2019, Andres et al., 2021). According to Jacobs (2009), Hong Kong is a metropolis with a booming sex market offering services such as love hotels, online sex workers and dating services, but sex talk has not been proliferated in Hong Kong as in the West. Sex minority, such as lesbian women, gay men, bisexual individuals, transsexual individuals, were commonly found to experience greater exposure to stress than heterosexuals (Hatzenbuehler, 2009; Badenes-Ribera et al., 2019). For the protection to sex minority, various parties such as religious organizations, parent, and teacher groups still held strong opposition that non-heterosexuality has violated religious, moral and Chinese Confucian family values (Kwok & Wu, 2015; Kwok, 2018; Kwok, 2019).

Education and training programmes have not challenged sexual prejudices (Chia & Barrow, 2016). There is lack of evidence-based programmes on sex education for schools in Hong Kong (Leung et al., 2019). The most updated guideline for sex education was proposed in 1997 (Fok, 2005). Most schools have offered sex education to some grades only and the contents have skewed towards teaching young people socially accepted morality in sexuality (Ho & Tsang, 2012; Cheng, 2018). Being an ungraded subject in the examination-oriented

environment, sex education has been marginalized as of lesser importance in Hong Kong (Fok, 2005; Zhan et al., 2013). Even in tertiary academic institutions in Hong Kong, it was hard to find the creative presentation of sexually explicit materials as part of media pedagogy (Jacobs, 2009).

Even at home, most parents perceive sex is a subject too “embarrassing and awkward” to talk about (Steinhauer, 2016). The focus of sexuality has also narrowed on the importance of procreation to ensure the continuance of family lineage, which is part of the duty of filial piety (Yu et al., 2011). In a nutshell, discussion on sexuality in Hong Kong is dominated by authoritarian societal expectations of heterosexual marriage.

The sex culture and its influence on the study participants.

The sex culture in Hong Kong can be claimed as conservative and anchored into the Chinese tradition. This social-cultural environment does not provide a habitat to nurture people to voice out their sexual needs and even to establish a teaching protocol to promote a positive attitudes and knowledge about sex. From the findings shown in the results of this thesis, sex education provided by social services staff was found to be grounded on the frame of traditional thought (chapter 5). People with intellectual disabilities were also found to have myths and “should attitude” about sexuality (chapter 6). Lastly, parent groups displayed conservative attitudes about sexuality (chapter 7).

For social services staff, the references for formulating sex education curriculum commonly are based on the idea of heterosexual and matrimonial discourse. Further, they may not consider any content of sex education going beyond the social-cultural expectation. As mentioned by one of the social services staff participants: “*we should not do our job in sexuality*

apart from our norm. We should consider how other people think about the content of sex education.” (S7)

Sex is a matter of duty for Chinese women (Yan et al., 2011) and everything about it requires it to be hidden away rather than talk about openly (Wang & Ho, 2011, Wang et al., 2018). Under this cultural umbrella, it is difficult for all the participants of this study to act as outsiders or use an etic perspective to stand outside the local moral codes to discuss on sexuality. Moreover, all the participants have lived, grown up and studied in this social environment. It is understandable that they would be prone to the emic perspective about sexuality. For example, one of the parents said: *“I would not talk about sex personally with my husband, but he (husband) does. Maybe I am conservative. I would not like to talk about on this topic. (P6)”*

For people with intellectual disabilities, growing up in a dogmatic and doctrinaire social-cultural environment, they demonstrated to have moralistic anxiety blended with “should” and “should not” attitude about sexuality, for example:

“It is not okay to see the characters in a movie kissing each other. I cannot fast-forward the movie clip because I live in a hostel. I will go to my room to wait until the scene comes to an end if there is such a scene.” (ID4)

“When there is a scene on the TV about sex, my parents or my siblings tell me that it is a forbidden scene for me to watch”. (ID5)

“I should not think about sex because it is only allowed after marriage”. (ID1)

The sex culture not only influences individual group but also the communication in between groups. It hinders communication about sexuality in social services settings. It also makes obstacles which impede the talk between parents and people with intellectual disabilities. The evidence collected from participants with intellectual disabilities and parents supports this claim:

“If two people with intellectual disabilities are in a romantic relationship, I will talk about safe sex. But I will emphasize the criteria for marriage, such as independence in self-care, money management, household work and most importantly, getting consent from their parents.” (S2)

“I would not talk about this (sex). If my kids do not ask me any questions about this (sex), I prefer not to raise the topic myself”. (P1)

“If you ask me to talk to him (son with intellectual disabilities) on what sex is, what could I do? If he asks me more in-depth about this (sex), it will be a bit embarrassing”. (P3)

In all, the shadow coverage of sexual education and the conservative sex culture make sexuality that is too embarrassing and awkward for people to talk about. When sex taboo intertwining with the tradition Chinese culture, this blended power further influences the

participants of this study to have complex feeling about sexuality. The next section will provide a detail analysis on this.

Feeling underneath of participants and the application of Interpretative Phenomenological Analysis

The thesis employs Interpretative Phenomenological Analysis (IPA) as one of the methods. IPA focuses on exploratory of people experience rather than testing existing hypotheses. The IPA question, for example, should be ‘How do people with intellectual disabilities experience sexuality?’ In this example, the researcher is interested in how participants frame their struggles with access – does it make them feel limited? To achieve this goal, IPA usually implies very close reading of the data, looking for detail in how people describe their experiences – not just a line-by-line reading, but sometimes also reading between the lines (Hefferson & Gil Rodriguez, 2011).

This research found that Chinese sex culture influenced the ranging and accuracy of knowledge about sexuality of participants. Using IPA, the research also revealed the underneath feelings among participants. For social services staff, they have to face the challenge created by inconsistent view on the handling of sexuality of people with intellectual disabilities. The inconsistency is between parents, or among the social services team. Through the investigation of the dialogue, social services staff was found to have a resignation feelings. For people with intellectual disabilities, they expressed their yearning for an intimate relationship and to have sexual needs the same as ordinary people. But they have faced constraints imposed by social services staff and parents. Their struggle with feelings was found latent in the words of the conversation. Lastly, although parents expressed their forever love to

their child(ren) with intellectual disabilities, they have prohibited their child(ren) to have a relationship to prevent any chance of procreation and exploitation. With the shame feeling accompanied, parents emphasized the “story of raising a child with ID must be stopped”.

Individual emotion and society are interdependent (Billett, 2006). Human emotions are believed to be the responses of contextual landscape and mediated by the meaning or value given to social cues (Fox, 2015). The next section of this chapter will discuss how the Chinese sociocultural environment intermingle with the underneath feelings found in the three groups of participants.

The Collectivistic culture on people relationship

Conflict exists in all kinds of institutions, but response is varied. People in collectivist cultures prefer a tight-knit social framework (Na et al., 2015). Individuals in that culture may expect their relatives, in-groups’ people to look after them in exchange for absolute loyalty (Hofstede, 1991). Meanwhile, collectivists avoid handling of divergent views expeditiously through open debate or discussion (Ho, 2007). Although Hong Kong remained under British rule for 150 years, studies revealed that Hong Kong people were still more collectivistic in orientation (Tam, 2003, Harris et al., 2005, Ho & Law, 2021).

From a theoretical perspective (Triandis, 2001; Triandis & Suh, 2002), four types of Individual-Collectivist culture orientations can be identified: (1) Horizontal Individualism (HI - uniqueness), where people strive to be unique and do their own thing; (2) Vertical Individualism (VI - achievement oriented), where people want to do their own thing and strive to be the best; (3) Horizontal Collectivism (HC- cooperativeness), where people merge with

their in-groups; and (4) Vertical Collectivism (VC - dutifulness), where people submit to the authority of the in-group and for whom they are willing to sacrifice themselves.

Parents of people with intellectual disabilities comprise as stakeholder but not the management of social services agency. Participants of the social services staff group tend to treat the parents as in-group members. One social services staff said: *"I am a father as well. I understand the concern to protect a child, particularly when the child has a disability"*. This horizontal collectivistic response might help to explain why the social services staff accept the parental resistance to granting more autonomy on sexuality for people with intellectual disabilities. Meanwhile, social services staff expressed their dissatisfaction towards the agency's hypocritical approach to sex education. Participants (the servicing/frontline staff) held the view that the management gave lip service to liberal ideals instead of supporting pluralist sex education in practice. But they dare not to express an opposite view. As one social service staff said: *"it is not necessary to do anything beyond the cultural norms and to embarrass the senior management"* (S4). The mixed feelings of disappointment and resignation towards the senior management can be regarded as a Vertical Collectivistic response. The Individual-Collectivist culture in both horizontal and vertical orientations provide an insight to understand the responses of social service staff. However, it is essential to further use the concept of *Guanxi* to peel another layer of belief on how Chinese react to a conflicting situation.

The Guanxi Chinese Culture

Guanxi (pin-yin in Mandarin) in Chinese has multiple meanings. It is not a bribe but the friendship, the interpersonal connection, or the interaction between the social individuals (Han & Han, 2017). *Guanxi* is a concept that cannot be completely defined and comprehended

by the western philosophy (Khan and Tang, 2019). Instead, *guanxi* is a kind of mutual responsibility, a long-term commitment, and a social investment created through different cordial efforts. *Guanxi* is a part and parcel of the Chinese history and culture. Looking at its influence on everyday business and even political activity, *guanxi* actually is the nexus of Chinese people (Zhang & Zhang, 2006; Guo et al., 2018).

Guanxi is an indivisible component of Chinese culture (Guan, 2011). To create the best value of *guanxi*, people must offer *renqing* (*pin-yin in Mandarin*). *Renqing* is a long-term investment and intangible social capital in the social exchange among Chinese people. *Guanxi* is social network weaved and bound by *renqing* that should not be narrowly evaluated by materials or money (Han & Han, 2017). Offering *renqing* emphasizes a sense of reciprocal obligation or indebtedness, in and between persons or parties. It is not only the simple reciprocal exchange of favour for the time being but also a long-lasting relation between the people or organization (Provis, 2008).

The Guanxi culture and its influence on the practice of social services staff

Participants of the social services have experienced a lack of collaboration among their team members towards handling sexualized behaviours of people with intellectual disabilities. For example, an assistant trainer participant mentioned the centre manager was unlikely to accept frontline workers' opinions: *"I thought I can handle some situations (challenging sexual behavior expressed by people with intellectual disabilities), but we have to wait for the approval of senior staff. However, they (senior staff) would frequently say that we need more time to think about a plan.....(S1)"*. On the contrary, another social services staff thought that the strategies adapted by frontline colleagues were overly conservative, for example: *"Frontline worker often prefer to apply prohibition on sexualized behaviours of clients with*

intellectual disabilities. Some colleagues (frontline staff) would say that allowing people with intellectual disabilities to masturbate, or access any erotic media, is to allow any fallacious ideas and behaviours to rampage arbitrarily in the centre” (S5)

Such conflicts do not benefit social services staff to work with the other parties to grant people with intellectual disabilities more autonomy on sexuality. However, when asked whether there had been any resolutions to those conflicts, no participant in the social services group mentioned any action taken to negotiate with parents and their colleagues to achieve resolution.

In healthcare services settings, talking about sex can be a sensitive and awkward topic (Ollivier et al., 2019). A review study (Dyer & das Nair, 2013) found that healthcare professionals did not proactively discuss sexuality issues with people with intellectual disabilities, particular to the opposite sex. On top of lacking knowledge and abilities, feelings of personal embarrassment or discomfort was the second major concern for healthcare professionals not discussing sexuality with service users. Furthermore, the report revealed that healthcare professionals tend to take the lead from the service users about sexuality rather than initiating discussions themselves.

To initiate a conversation about sexuality potentially creates an awkward social situation, which may impact personal reputation in Chinese working context (Taormina & Gao, 2010). More importantly, to initiate discussion on sexuality may provoke anxious atmosphere in the workplace, which potentially influences the *guanxi* within the working team. To handle conflict in *guanxi* culture, the collaborating approach can be a perfect solution leading to

satisfaction among colleagues. Compromising for seeking a balance among different parties has significantly contributed to the harmony in a *guanxi* network (Peng & Silva, 2018). Therefore, discrepancy on the handling of the sexual needs of people with intellectual disabilities exists, it would be a “wise choice” for any involved parties not to keep the discussion going or even confront the idea of others.

When disagreement is between frontline staff and agency policy, avoiding or obliging strategies to manage the conflict perhaps are best fitting the expectation in *guanxi* culture. Bargaining on issue about sexuality, as aforementioned, will potentially create embarrassment in the workplace. Chinese social groups respect authorities in the hierarchical structure and it is common to see staff demeanours bound by their social ranks, governed by authorities and rules (Yao, 2014). Chinese employees were found to respect higher position when resolving conflicts (Wang et al., 2016). Although not protesting for the autonomy of clients may contradict the notion of a helping profession in its broad contextualized approach to addressing human needs (Barnes & Hugman, 2002), given to the expectation from Chinese hierarchical culture, subordinates usually would sacrifice their own interests (Zhang & Zhang, 2012; Huang, 2016). In addition, social services staff not protesting against a sensitive issue can be regarded as offering a *renqing* to senior management for maintaining their *guanxi*. Obtaining good *guanxi* from senior management who could manipulate work conditions or opportunities, subordinates can expect a *renqing* in return at a later time. This kind of practice of exchanging favours is fundamental and deeply rooted in the *guanxi* network. Lastly, breaking the harmony and equilibrium will be considered as betrayal and punished (Wu et al., 2020)

The Guanxi culture and its influence on the communication between the staff and parents

Avoidance of conflict exists between social services staff and parents as well. A recent local study (Wong, 2021) reported that among the issues for caring for people with intellectual disabilities, parents granted the least autonomy to their child with intellectual disabilities in dating and sexuality. Under the *guanxi* culture, to protest the autonomy of sexuality for people with intellectual disabilities, would become an action against the expectation of a stakeholder. On the contrary, not to confront the restriction imposed by parents can be regarded as a manifestation of maintaining good *guanxi*. According to the manager of the social services staff group, she emphasized the primacy of parents' wishes: "*no matter what the parents of people with intellectual disabilities say, we have to follow them*" (S3). Another male trainer held a similar view: "*The final decision to allow people with intellectual disabilities to have a romantic relationship lies in the hands of parents, even if their view is different from the person with intellectual disabilities.*" (S6)

Typically, social service relationship requires empathy (King, 2011; Green et al., 2017). Practitioners should develop an empathic understanding as a way of knowing clients through their own frames of reference. This empathy serves the purpose of interpersonal communication in the perceptual field through shared phenomenological experiences (Cheung, 2017). Although 'empathy' has been considered a universal key to motivating changes in the helping process, the Chinese tend to understand empathy in a different way than Westerners (Cheung, 2014). Specifically, empathy in *guanxi* is anticipatory in nature and building of *guanxi* between two persons is more sentimental and intuitive. Offering *renqing* in *guanxi* is not only a reciprocal favour, but also an affectionate response. Therefore, offering *renqing* by

the social services staff to the parents, or vice versa, is, in fact, an empathic gesture (Cheung, 2017).

The social relationship in the Chinese context should not be deviated from *guanxi* and *renqing* (Chu, Tsui, & Yan, 2009). Hence, social services staff cannot acquire trust and rapport from parents by simply acting as technocrats with expertise in tackling human problems by procedural knowledge. Under the same cultural roof, to a great extent, social services staff recognize the shame and sexual taboo concept intertwined in the family with member with intellectual disabilities. While there are lots of agendas to work on, it is not necessary to “open the can of worms” that would create embarrassment, and potentially impact on the *guanxi*. In this regard, the concept of *guanxi* and *renqing* can be highly instrumental and purposeful in understanding the complexities around sex and people with intellectual disabilities. A stick has two ends. *Renqing* facilitates the cultivation of *guanxi* but challenges the prestigious status of social services professionals and impacting the mission for protesting the rights of client. Nevertheless, for the social and health care services, they are truly relationship based. Therefore, in the Chinese context, the very essence of *renqing* and *guanxi* must be upheld for smooth daily operation (Cheung, 2017).

The Chinese Concept of Filial Piety

Confucianism provides a view of the cosmos and social order that legitimates the Chinese patrilineal, patrilocal, and patriarchal family system (Das Gupta, 2010). Filial piety (*xiao*) is the core pillar of Confucian ethics (Ho, 1996; Yeh & Bedford, 2019). The pre-eminence of filial duty is clearly demonstrated by a classical Chinese saying: “Among all virtues, filial piety is the first”. Filial piety also blends marriage and procreation together. A Chinese concept “without male offspring is the worst form of impiety” illustrates the obligation

that a Chinese should get marriage and to have children to maintain the family bloodline (Li et al., 2015). This Confucian ethics about the continuation of the family line mushroomed everywhere in Chinese community (Ikels, 2004). However, this cultural norm implicitly embeds a stigma against any adult with disabilities who remains single and not able to fulfil the duty of filial piety.

Chinese filial piety emphasizes the patrilineal system. Chinese family system is organized hierarchically so that men and older generations have considerable power over women and younger generations (Ebrey 2003). The Chinese character “*xiao* 孝” comprises of an upper and a lower component, which refers to the dynamic between senior and younger generation. Further, filial piety stresses parents’ duty of caring for children, while children must repay the immense debt that they owe to their parents for feeding and raising them. According to Knapp (2004), this kind of caring and repay was a ‘reciprocal bargain’ between parents and children.

The Chinese concept of filial piety and its influence on people with intellectual disabilities

The aforementioned “reciprocal bargain” is not just about children giving back food or materials to parents. In nowadays Chinese society, people have high expectations on achievement-based domains such as academic performance or professional achievement (Barber & Rao, 2005; Guan & Ploner, 2020). The “tiger mother” culture creates expectation on younger generation having good academic performance, acquiring professional or managerial position, and even achieving admirable social status (Zou et al., 2013). The Chinese proverb, “*wang zi cheng long*” is a portraiture capturing the socio-cultural meaning of this

phenomenon. In English, it means that parents wish their child could become a “dragon”— the totem symbolizing imperial power and blessed life in Chinese culture (Liu & Wang, 2015). To assess this phenomenon specifically in Hong Kong context, Shek and Chan (1998) have revealed that parents projected that an ideal child should have a good relationship with their parents and good academic achievement. Academic excellence raises the social value of children, and brings “faces”, reputation, and prestige to entire families (Zhang, 2020.) The statement made by one of the parents echoed this idea: *“Every parent hopes their children will have a bright future. I admit that I am that type of person..... But in reality, my son (with intellectual disabilities) cannot make it.”* (P6).

Moral challenges are particularly salient for parents and teachers who are concerned with the cultivation of a moral child. In Chinese context, a child should meet the moral demands between achieving individual market success and maintaining traditional values (Tamis-LeMonda, 2008; Zhang, 2020). It often requires self-sacrifice for social and collective purposes, which means to honour one’s family or even the country (Liu, 2019). Hence, becoming a good child, obedience, docility, acceptance of authority, conformity to accepted social norms, are the most important concepts and rules in Chinese societies (Chen & Lau, 2021).

People with intellectual disabilities have limited capacity, for example, limitation in literacy and numeracy. When this situation bundles with the negative attitude from the community, it restricts their social participation, or even the establishment of a broader social network as ordinary children have (Abbott and McConkey, 2006). Along with this unfavourable situation, it is not easy for a person with intellectual disabilities to do the ‘reciprocal bargain’ by repaying the materials debt he owes his parents. Nevertheless, compliance with family rules is another kind of repaying. In the context of handling personal

need in sexuality and romance relationship, people with intellectual disabilities have repaid their parents by obeying the doctrine of not having any relationships. Two stories were told by people with intellectual disabilities echoed to this situation:

“I want to have a family. My brother and sister have families. I feel so envious. But I cannot. I have no money, which is essential for marrying a girl. And my parents said that I should not get married”. (ID1)

“I felt good when he touched me (coyly smile when talking about this). But my father did not like him. Both my parents said that it is not good for me to be in a relationship. But my brothers have. I feel lonely when I visit them.” (ID2)

Although the Chinese sociocultural contexts undergo rapid changes and have even evolved in recent decades (Chan & Rao 2009), in today’s China, the widespread and dominant expectation is that a child should perfect oneself morally and socially (Li, 2010). Clearly from the findings of this study, people with intellectual disabilities are struggling to have a romantic relationship, or to express their sexual desires. However, they illustrate the qualities of a “Good Chinese child” to be obedient, to accept regulatory authority, and to conform to the doctrine of norms of filial piety.

The concept of Chinese Face

When a child is born, the life of the family changes significantly and each of its members must adapt to the new situation. When the child is born with a disability, in addition to regular adaptation, the family must cope with challenges, stress, disappointments, and shame

which may lead to a crisis or even disruption of family life (Hu, 2020; Sim et al., 2021). Those disappointments and shame, when intertwine with the Chinese culture about face, create another layer of challenge to the Chinese family that makes the situation about sexuality more complicated.

The Chinese face concept emerges as a fascinating and intriguing topic both to Chinese and Westerners before it has become a research topic for academia (Li, 2017). In the 18th Century, Smith (1894) stated the word face in China that does not simply signify the front part of the head, but is literally a compound noun of multitude, with more meanings than we shall be able to describe, or perhaps to comprehend. The notion of face is highly salient in Chinese society (Hinze, 2005; Qi, 2011), and a variety of expressions relating to the concept are used ubiquitously in the Chinese language to explain social and personal behaviours. Many different cultures have a notion of face, however, perhaps few of them have as much cultural elaboration on face as the Chinese. (Yang, 1994).

In real life, there is always a possible mismatch between what one wishes to be and what a person is in reality (King, 1988; Spencer-Oatey, 2007). This mismatch may cause a person to lose his or her image, feel embarrassed, particularly for those who desire to present a good image to impress others. In Chinese society, people are expected to have a respectable and admirable reputation, or in other words, an honourable face (Randau & Medinskaya, 2015). For covering up any dire situations, such as being unable to climb the social ladder, lacking good connections to people with power, Chinese would like to fight an admirable image, for example, being praised in front of the others. (Li, 2017). In traditional Chinese society, an individual is encouraged to strive to become a gentleman or a superior person with a noble character and reputable image (Hu & Broome, 2020). Founded on this basis, individuals would

try their best to climb to a respectable and admirable social position to “gain face”. Also, Chinese have the desire to “protect face” by not “losing it” by behaving according to the social norm (Shi et al., 2011; Li, 2017).

Face and shame on parent with a child with intellectual disabilities

Parent’s raising and caring for a person with intellectual disabilities are often confronted with multiple challenges, such as physical disorders, emotional health problems, and social dysfunction (Yang, 2015). In Chinese culture, people with disability are stigmatized as not able to make a meaningful contribution to society (Huang et al., 2020). To have a child with disabilities also represents the violation of the belief of reciprocal parent–child relationship (Knapp, 2004; Sit et al., 2020), which leads to the circumstance of losing face for the family. Therefore, stigma associated with people with intellectual disabilities has been shown to inevitably increase the burden for the family caregivers (Chiu et al., 2012; Chou et al., 2009).

Internalized self-stigma among family caregiver, is one of the most damaging consequences of stigma, it is conceptualized as internalized feelings of shame, embarrassment, and guilt, leading to perspectives of self-worthlessness, and social withdrawal of caregivers who are impacted by intellectual disabilities related stigma (Chang, 2009; Chiu et al., 2015; Mak & Cheung, 2012). Shame is an inner and endured experience that can be the worst consequence imposed on caregivers because it impacts self-esteem and people feel unfit to live in their own communities (Gilbert et al., 2004). The feeling of shame has been the greatest barrier to Chinese people expressing their difficulties publicly and seeking help (Leong & Lau, 2001). Studies have revealed the relationship between internalized self-stigma, shame, and the perception of Chinese to lose social face (Chang, 2009; Chou et al., 2009; Chiu et al.,

2015; Mak & Cheung, 2012). Cross-cultural studies have suggested the feeling of shame, is a key emotion for Chinese people/families and results from the face culture, based on Confucianism (Ho et al., 2004). Research has revealed that parents of people with intellectual disabilities felt faceless and shameful and perceived to be marginalized in the public, such as being stared at or blamed by others for inappropriate behaviour conducted by their child with intellectual disabilities (Yang, 2015). Even worse is perceiving discrimination from families, which has a more profound effect on caregivers than that from the public, because Chinese people highly value family connections (Qiu et al., 2017).

As aforementioned, Chinese parents wish that their child become a “dragon” (Wu & Singh, 2004; Wang et al., 2019). Failing to fulfil these expectations will elicit the facelessness for the whole family in the hierarchical society (Lin & Yamaguchi, 2011). For people with intellectual disabilities, due to the deficient cognitive functioning and the restriction imposed by the stigmatizing attitude from the public, it is a challenge for them to be a “dragon” child for their parents.

Cultural norms affect the choice of coping strategies that individuals can utilize in any given situation (Kayser et al., 2014). Under the Chinese face culture, the alternative of gaining face is to prevent losing it. For the participants of the parents’ group, it can seem that they have shifted the focus on the performance of the child with intellectual disabilities to daily living tasks, instead of academic or work achievement. This kind of coping helped to ensure the child with intellectual disabilities to behave as a “polite child” and “not a fool” in front of others. And most importantly, echo the theme of this study, a “polite child” would not do any sexual expression that would embarrass people. Two of the responses from the parents provides relevant examples:

“My idea is to provide training for my ‘daughter’ on self-care, cooking, and obtain vocational training and a hostel place for her. If there is a scene related to kissing or hugging on TV, I would ask her to look away and tell her that it is forbidden”.

(P4)

“It is so embarrassing if my son tries to hug someone. The best way to handle this is to deal with it at the beginning by not allowing him to do so.” (P7)

Sex taboo surrounds Chinese culture. Breaking the unspoken rule in this culture may induce the loss of face. Echo to this, the coping strategy of participants of parents’ group was to minimize the circumstance related to sexuality that is believed to be shameful by others. Participants mentioned that they would use various kinds of ‘reasons’ to dismiss the requests from their child with intellectual disabilities to develop any kind of romantic relationship. Further, participants displayed self-stigmatized attitudes that nobody would like to engage in a relationship with their child with intellectual disabilities. In addition, under the cultural umbrella, sex is a matter about matrimonial and procreation. This belief captivates a parents’ mind, thus allowing their child with intellectual disabilities to have a relationship is equivalent to having deficient descendants. The parents firmly stated that the disability journey and “family tragedy” should be over. The statements made by some parents clearly reflected this pessimism and disappointment:

“If they really think about marriage and sex, it may result in them having children.

It is so sad. Why go to the trouble of having another disabled generation?” (P1)

“It is very painful to have a child with intellectual disabilities. Marriage for him?

I think that the story should end here”. (P5)

This kind of dismissal reveals a shame feeling of being the parent of a child with intellectual disabilities. Having a family member with intellectual disabilities, in Chinese culture, galvanizes the situation of losing face and the feelings of shame. Shame is a very powerful force that potentially immerses parents in negative self-evaluation. This power of internalized shame, combining with the notion of paternalism and filial piety, formulating the discourse that people with intellectual disabilities should have lesser autonomy in sexuality, both accepted by parents and people with intellectual disabilities. The discourse is an invisible shackle fastened to people’s mind to prevent them escaping the cultural boundaries.

Dramaturgical perspective and sexuality of people with intellectual disabilities

This chapter reported the knowledge and attitude about sexuality of three groups of participants: people with intellectual disabilities, parents, and social services staff. Chinese sex culture is believed to play a role in influencing adequacy and degree of open-minded about sexuality of the participants. By reviewing the footage of participants’ dialogue, in interpretative phenomenological term, the ‘onion skin layers’ overlying their significant lived experience were peeled away (Lewis et al., 2016). On the one hand, three underneath feelings of the three groups, namely resignation, struggling, and shame were found as well. On the other, all parties acknowledge sexual need that is normal for people with intellectual disabilities but have not taken specific action against those negative influence, or to proactively strike for the

autonomy of sexuality of people with intellectual disabilities. Regarding the “not to take action” situation, a question springs to author’s mind: “Would it be a reason lying hidden within the three groups of participants and influencing this tripartite action?”

Dramaturgy, a sociological perspective proposed by Goffman, commonly used in micro-sociological accounts of social interaction in everyday life may help to explain this tripartite action. According to dramaturgy, people engage in social interactions with the aim to keep away from embarrassing others or being embarrassed. Goffman creates a theatrical metaphor, defining human beings presenting themselves to others based on cultural values, norms, and beliefs, and as a connection between the kinds of acts that people perform in their daily lives as a theatrical performance (Goffman, 1959). There is a front region that individuals perceive themselves as actors on the front stage in a theatre. It is how we behave and interact when we have an audience. Front stage behaviour reflects internalized norms and contextual expectation for people’s behaviour that can be highly intentional and purposeful, but also habitual or subconscious. For example, across different culture, it is almost universal for people to wait in line for payment consciously in supermarkets. However, it is not difficult to find Chinese silent students in a sex education classroom. Even the silent students may be comparatively more knowledgeable among the class, Chinese students commonly listen to the teacher quietly, attentively, and respectfully; while western students take active roles in expressing their views and asking questions (Hodkinson & Poropat, 2014).

The front stage emphasizes desired impressions management, which is about how oneself manages others’ attitude and behaviour (Krisnawati, 2020). In other words, impression management aims to produce a particular impression, whether intentionally or unintentionally, on other people and to enable the interpretation of the identity created. Jones & Pittman (1982)

have mentioned that during the impression management process, a person would have a strategy for self-promotion, ingratiation, intimidation, exemplification, and supplication. Echoing to the aforementioned silent students' phenomenon, the student remaining silent, on the one hand, can avoid public embarrassment of talking about sex. On the other, the student can maintain a humble image that is not showing off in front of others, an image that is salient in the value of Confucianism (Hodkinson & Poropat, 2014; Dong, 2017).

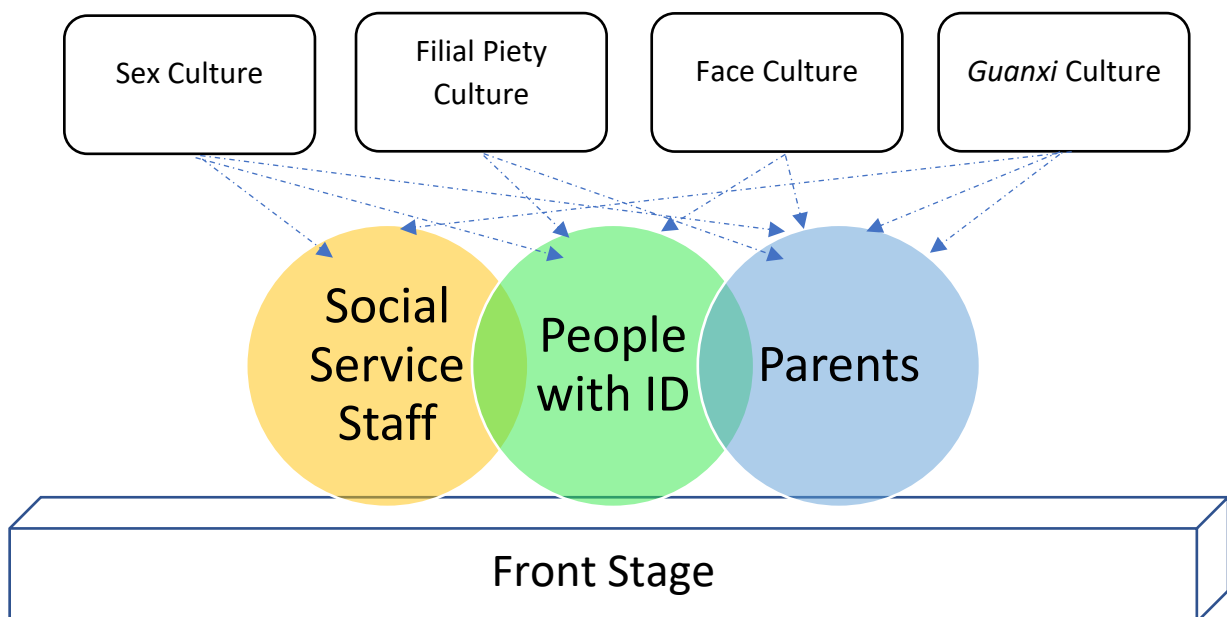
Front stage performance typically follows a routinized and learned social script shaped by cultural norms (Harrison, et al., 2018). Social scripts are social and cultural norms or intrapsychic maps that provide guidance on how to feel, think, and behave, and people's lifestyles (Wiederman, 2005; Tan, 2015; Wiederman, 2015). Cultural script is not a subject that people learn via deliberate study (Tan, 2015), but rather through a lifetime of immersion. This kind of learning is a transmission, or an exchange within an individual, family, social, or cultural group. The script messages are transmitted at the overt and conscious, but also unspoken, subconscious, or even alter adult thinking during the intrapersonal cognitive process (Campos, 2015). Without awareness of this force, humanity will continue to believe that the cultural value is inevitable, especially when it is not experienced as an option or within conscious adult control. In the context of this study, social services staff may unconsciously learn how to react to a workplace conflict from the guanxi cultural. For people with intellectual disabilities, being a "polite child" can be regarded as an unconscious act to fulfil the expectation of filial piety. For parents, exercising parental authority perhaps is the unconscious coping for protecting face of a family with a member with disabilities. All those reactions reflect an exchange and transmission of unconscious learning within the family, working context, and the Confucianism value system.

Borrowing the language of dramaturgy from Goffman (Green, 2008), the tripartite scripting model, composed by three conceptual dimensions: cultural scenarios, interpersonal scripts, and intrapsychic scripts, provides further explanation on sexuality (Laumann & Gagnon 1995; Simon & Gagnon 1986; Simon & Gagnon 2007). The cultural scenarios refer to the captures of the culturally specific instructions for sexual conduct (Laumann & Gagnon 1995; Bowleg et al., 2015). For interpersonal scripts, it refers to the patterned negotiations of sexual activity between involved parties (Irvine, 2003). Finally, intrapsychic scripts point to individuals' meaning given to as sexual pleasure, sexual conquest, passion, and emotional intimacy, which are influenced by cultural and interpersonal codes in sexual scenarios (Laumann & Gagnon 1995; Jones & Hostler, 2002; Seal et al., 2008). When comparing with the western, the Chinese sociocultural feature embedded in Hong Kong creates a script that influences Chinese people's expression of erotic desires and sexual fulfilment (Zhang et al., 2022). In other words, the "not to take action" of the tripartite participants can be the complex composition influenced by Chinese sex culture, the particular way of negotiation in the culture, and intertwined with personal meaning related to sexuality.

In the second chapter of this thesis, it mentioned that an "unintended invisible hand" has influenced the autonomy of sexuality of people with intellectual disabilities. Generated by the power of Chinese Confucianism script, the unintended invisible hand probably is the force influencing the unconscious behaviours of the three parties of this study. This invisible force controls the undeliberate tripartite reaction and demonstrates the interaction transmitted at the unspoken, and unconscious levels of communication (Campos, 2015; Tan, 2015).

Merging the analogy of unintended invisible hand with the dramaturgical perspective, the three involved parties of this study collaborated to perform a “Puppetry Front Stage Show” (Figure 8.1). This puppetry show is an analogy that each party serves as a puppet controlled by the invisible hand of the puppeteers, which are the overarching cultural values. The control over the puppets is by transparent wires or strings (dotted line, a metaphor that the tripartite performance is an unconscious or habitual act. The overlapping circles reflect the interconnectedness of the three parties as a tripartite troupe performing the show together under the Chinese sex culture, reacting to repression or a conflicting social situation.

Figure 8.1 Illustration of Chinese social-cultural environment and its influence on the tripartite front stage performance in dramaturgical perspective



Chinese sex culture and the show

Sex is still somewhat of a taboo topic in Hong Kong. This doctrinaire culture does not promote a good habitat to nurture people to openly voice out their personal sexual needs. Breaching this doctrine is impolite and would insult personal reputation and even result in loss

of face. Human sexuality is an area that is lacking in training which leads to challenges in communication among health care professions (Leung et al., 2019). In the working context, ‘who in the office has the confidence to open that can of worms?’ To save personal face, it is not a wise choice to initiate, or to insist the discussion about sexuality of people with intellectual disabilities. Therefore, in the puppet show, discussion on sex should not be a line spoken by any actor or a scene under the limelight.

Chinese *guanxi* and the show

Guanxi and *renqing* heavily influences the social work practice in Chinese society (Wang & Pak, 2015). According to Lauw (2016), Australian Chinese elders would join an activity based on *guanxi*, which they have developed with the activity’s coordinator over time. The elders offer to attend the session out of *renqing*, even though they were unsure of what the session entailed. This reciprocal exchange is also the essence for the tripartite relationship of the three parties involved in this study. One of the female participants of people with intellectual disabilities mentioned that she rejected a boy who would like to kiss her. Her concern is that it is not allowed by staff: “.....if this is discovered by staff, they would scold me” (ID2). This kind of compliance, first, is part of the virtues of Confucianism about “*li*” (propriety/curtesy/politeness) that a services user should respect to authoritative figures (Cheung, 2017). Second, it also about an offer of *renqing* to the social services staff. To give *renqing* to social services staff, the reciprocal return for people with intellectual disabilities possibly is to have lesser restrictions in other areas or more opportunities to join social activities. As a reciprocal relationship, social services staff also give *renqing* to people with intellectual disabilities. For example, they may “turn a blind eye” if they found a person with intellectual disabilities masturbating in the hostel bedroom, or to use a gentle tone to ask a person with intellectual disabilities not to browse porn website in the living room of a hostel. Offering such

kind of “allowance”, or *renqing* may help the social services staff to form good *guanxi* with people with intellectual disabilities.

Comparable to the norm of reciprocity and the social etiquette of interpersonal obligations, *guanxi* and *renqing* are cultural logics of particularism and their associated cultural repertoires (Chan & Yao, 2018). Since autonomy of sexuality is the least concern of parents of people with intellectual disabilities in Hong Kong (Wong, 2021), the non-reactive action taken by social services staff that can be regarded as a gesture to give *renqing* to parents of people with intellectual disabilities. In daily health care and social work practice, there are many other tasks, for example, vocation rehabilitation, lobbying for more residential quotas, etc., to work on. The formation of mutual support group is one of the examples. In addition to open recruitment, social services staff might invite some parents as core members to oversee the growth of the mutual support group in a positive way. To be in a *guanxi*, the invited parents might regard the act of invitation and participation in such a mutual support group as a token of reciprocal benefits. It means the parents give *renqing* to the staff. Some clients who have previously been helped by social workers might also consider participation as a form of return of *renqing*. Moreover, for someone who has not been served, the act of joining perhaps reflects the mentality of reciprocity that the social worker should provide at least a return favour as a later exchange.

In the analogy of puppet show, the sex and *guanxi* culture controls the three parties. The tripartite troupe offer *renqing* to each other by not talking about sex proactively. This “peace and tranquillity” does not carry a theme on bitterness or stinging. Instead, it echoes to the concern for harmony in Chinese conflict management. The tripartite cooperation illustrates the dynamic in *guanxi*. A harmonizing process in *guanxi* is an art-oriented in nature for

resolving conflicts in Chinese culture. Above all, the tendency to avoid face-to-face conflicts and to value harmonic interpersonal relationships is deeply rooted in the mindset of Chinese people (Chin & Liu, 2015).

Shame and the show

Shame is an interpersonal orientated feeling. Its associated behaviours are highly related to social norms (Lam et al., 2006). Due to social stigma, social expectations, and face concerns, Chinese families with a member with disabilities commonly experienced the feeling of shame (Chiu et al., 2015; Yang, 2015; Lui & Rollock, 2018). The shame and face social scripts have formed a co-play for parents and the people with intellectual disabilities of this study. The Chinese patriarchal tradition emphasizes top-down authority granting to parents. Based on this tradition, Chinese parents exercise their authority to demand that their child, whether or not they have disabilities, exhibits self-control and discipline (Li et al., 2018; Yang, 2015). This action is to avoid the embarrassment of a losing face performance in the front stage (Goffman, 1959; Shulman, 2017). Therefore, given the situation as a family gathering, participating activities in a public place, or even the mental rehearsal of any social circumstance (Henriksen & Mesel, 2021; Yang, 2015), Chinese parents who participated in this study demonstrated the mentality that they should control their child with intellectual disabilities to be a well-behaved kid in front of others. Thus, minimizing the opportunity to get involved in a shameful circumstance and in-turn prevent damaging 'face' of the family

Chinese people have been taught to exercise self-control, inhibit self-interests and personal desires from a young age for minimizing the opportunity of losing family face (Li et al., 2018; Vuuren & Aldersey, 2020). Echo to the concept of reciprocal bargain, Chinese must do their best to return to their parents. As a person with intellectual disabilities, the best way to

give the return is to follow the parental dogma, even if it may contradict to personal wish and desire. He or she should not perform any act that would, or potentially would damage the face of the family. As illustrated in the findings, people with intellectual disabilities clearly expressed their desire to have a relationship. But they all surrendered their desire to the restrictions imposed by their parents. And even some kind of disappointment noted from their facial expressions, nobody with an intellectual disabilities dares to express a strong counter view to their parents' restraints. Simply, they just comply. Corresponding to the idea of impression management, the child with intellectual disabilities co-plays the puppet stage performance as a good kid for saving the face of the family.

The puppeteer for this scene is the shame and face culture. Again, it is not a tragedy that depicting all involved parties as a victim of destiny. Instead, the show demonstrates family harmony. It illustrates the family closeness, congeniality, cooperation, and mutuality. All these are the most valued attributes of family relationships in Chinese culture (Kavikondala et al., 2016). Moreover, family well-being is a major indicator of a Chinese harmonious neighbourhood. In Chinese culture, harmony and cohesion within a family is one of the most critical dimensions to influence social harmony in society (Chan et al., 2011).

An equilibristic and harmonic denouement

Culture script components can be generalized by collective subcultural levels of communication (Campos, 2015) and can be positive or negative (Salters, 2006). The underlying feelings of the three parties: resignation, struggling, and shame, can be categorized as negative emotions generated by the cultural script. There remains, however, a positive side of the tripartite puppet show. The tripartite troupe collaborates in a stage performance complementing the theme of equilibrium and harmony, a core philosophy in Chinese culture.

Equilibrium and harmony have been highly valued by Chinese people since ancient times (Zhang & Constantinovits, 2016). Confucianism directs people not to pursue a perfect scientific model for “absolutely” resolving contradictions or conflicts (Li, 2012; McElhatton & Jackson, 2012). The pursuit of harmony cultivates one’s morality, constructs one’s family values, governs an organization’s hierarchy, and even stabilizes the nation. For social services staff, keeping their resignation at a personal level enables them to benefit from good guanxi with all stakeholders. This reaction further promotes the core value of maintaining harmony at the organizational level of the social service agency.

People with intellectual disabilities struggle, but are “rewarded” by praise for being a good child. That they do not bargain with social services staff or parents, this further contributes to harmony in the social services unit and protection of the family’s face. Shame is a negative emotion. People who experience shame usually try to hide what causes their shame. Keeping the can of worm sealed reduces conflict and dilemmas for the family, although it suppresses the right of the person with disabilities to enjoy the positive experiences of sexuality and intimate relationships. Follow the Confucianisitic culture, it is a crucial and positive act to hunt for a harmonious family life.

Across this thesis, sexuality in Chinese culture displays itself as a double-edged sword. Sex is a taboo that would evoke embarrassment in social situation, interpersonal conflict, or even trigger people’s shame feeling. The opposite side of those pessimistic features is the formation of an equilibristic and harmonic tripartite alliance, which is a higher concern and end goal from the entire social-cultural environment.

The puppet show analogy is not to imply that the “puppets” are merely dolls with no free will. If individuals are constrained by social-cultural interaction to present themselves in their performance, the examination of individuals’ development through Goffman’s dramaturgical lens is not a cynical viewpoint (Bray, 2021). As a symbolic interactionist, Goffman, in fact, asks how people present themselves within the domain of social interchange governed by cultural rules and conditions (Goffman, 1959). This article examines the functions of the tripartite dynamic in the context of Chinese cultural norms on sexuality. It further reveals the alliance through respecting cultural expectation and creating an equilibristic and harmonic mutual network, which is the priority and end goal of the entire social-cultural environment that the participants live in.

Chapter Conclusive Summary

Three groups of participants: people with intellectual disabilities, parents of people with intellectual disabilities and social services staff working in this field were interviewed. Their knowledge and attitude about sexuality and its relationship with the Chinese culture were reviewed. Further, by employing the interpretative phenomenological analysis, the underneath feelings of the three parties were discussed. For all parties, they acknowledged the importance of sex and recognized it was a part of being a human being. However, the responses, were not pointing to the side of facilitating people with intellectual disabilities to enjoy sexual and intimate relationship. The contradiction should not be viewed as a negative motive from either of the parties. Instead, from the dramaturgical perspective, it was a tripartite puppet show. The puppeteers were the human relationship concepts of Chinese culture. The ultimate goal of the

show was to achieve the Chinese value of equilibristic and harmonic relationship. The tripartite alliance cooperated smoothly in the daily life context, and not a total-loss game to any parties.

In the next chapter, the final session of this thesis, the text will present the recommendation, strength, and limitation of this study. At the final part, it will provide an overall summary of the thesis and conclusion of this doctoral study.

Chapter Nine

Closing: conclusion, implications, and limitations

Chapter overview

In discussing the lessons and experiences learnt from this doctoral study, this thesis captured the richness of the phenomenon about the sexuality of people with intellectual disabilities, a complex account of participants' experience. This chapter constitutes the implications of and recommendations that arise from the study findings associated with the challenges and opportunities for sex education, social services practice, and research. Subsequently, this chapter presents the strength and limitation of this study. Prior to the closure, is the conclusion of the study.

Implication and Recommendation

The current findings represented experiences, attitudes, and feelings of sexuality of people with disabilities, from three groups of participant: people with intellectual disabilities, parents, and social services staff. Chinese socio-cultural factors have influenced the tripartite group dynamic on the handling of the sexuality of people with intellectual disabilities. Those factors were the conservative attitude about sex, collective and Confucianism concept on interpersonal relationship, and filial piety. Value in a culture is analogous to a major plate on Earth, which is hard to be shifted by a single stroke. With careful consideration of the cultural context and the subtle feelings experienced by all parties, some recommendations about sex education and social services practices are discussed below.

Implication for sex education and social services practice

In most Chinese countries, there is a dearth of evidence-based and mandatory sex-education programmes (Leung et al., 2019). From the result of this study, the social services staff had to “simmer” their own sex education protocol, which lacks empirical support. Those situations indicate the significance of transforming the current sex education programme in Hong Kong to a holistic, replicable, and sustainable sex education protocol. The protocol should empower people with intellectual disabilities and their trusted adults to build a supportive environment for sexual health promotion. From a sexual health perspective, sex education protocol should address the issues including sexually-transmitted infections (STIs) (Marrazzo et al., 2018), pregnancy and contraception (Widman et al., 2018; Lunde et al., 2017), and abuse and violence (Reid et al., 2020). For a holistic view, sex education protocol should be revamped as relationship and sexuality education (RSE) programmes. RSE programme is a comprehensive protocol addressing knowledge and information ultimately leading participants to a satisfying and fulfilling adult life (Burns et al., 2019). According to research, RSE programmes broadly focused on the personal dynamic that enables people to make decisions based on facts or information about sexuality, relationships, promoting resilience and knowing where to access help and support when necessary (Janssens et al., 2020). For people with intellectual disabilities, on the one hand, RSE aims to enable them to have adequate knowledge on sexuality and to make informed decisions about key aspects of their lives (Alonso-Sardón et al., 2019). On the other, the RSE programmes should also enable people with intellectual disabilities to pursue and maintain a healthy, intimate and meaningful relationship that may include sexual expressions. Moreover, in response to contemporary society, the RSE programmes should also cover same-sex relationships, online presence and cyberbullying features (Reynolds, 2019). At the policy level, the RSE programmes should not only address the needs of children and young people but be extended to nurture people with intellectual

disabilities across lifespan (Brown et al., 2020). The policy makers in Hong Kong can take a leaf out of the UK's approach. Where the guiding policy is that all people have the same right to access education programmes, the UK Government have embedded evidence-based RSE programmes into school curriculum for pupils with and without disabilities (Reynolds, 2019; Al Hazmi & Ahmad, 2018).

To make the RSE programmes effective, people with intellectual disabilities, parents and professionals should consider working collaboratively to enrich the programme content, delivery and evaluation of the specific needs and concerns of people with intellectual disabilities (Brown et al., 2020). In addition, policy makers should be cautious on the embedded sexual content under Chinese milieu. Further to the findings of this study, the adoption of sex education protocols from western culture, but with more an integrationist rather than assimilationist approach, may be useful.

Continuous trainings on sexuality issues are essential for social services staff. The training should have the vision to enable the practitioners to be familiar with the arguments for and against different views around sex education (Leung et al., 2019). As aforementioned, the RSE programmes should be implanted into the school curriculum for pupils with and without disabilities, it is also essential to equip schoolteachers with the knowledge, skills, and confidence to affiliate the effective delivery of RSE programmes. To encourage the maintenance and expansion of skills and knowledge, the policy should consider sex education and training as part of continuing professional development (CPD) programmes.

Delivering evidence-based information about sexuality to people with intellectual disabilities is also a crucial task. Nonetheless, the study revealed that people with intellectual disabilities did not demonstrate significant resentment of their struggle on the restriction of sexuality. In response to this special circumstance, any approach overemphasizing the empowerment on the right on sexuality of people with intellectual disabilities potentially is hardly to get the expected the results. In a collectivist culture, where sex is taboo, it would be wise to make a “detour”. Detour in the field of empowerment refers to not directly challenging the righteousness of relinquishing the control over people with intellectual disabilities. Instead, empowerment works on an alternatively route to potentially assist people with intellectual disabilities increasing the control of their sexual lives.

Echoing to the idea of “detour”, according to research, some individuals may feel psychologically empowered when they interpret and perceive their lives as meaningful, feel free and competent to determine their lives, and envisage success with a sound impact (Fock et al., 2011). In line with this, encouraging people with intellectual disabilities proactively participate in leisure activity is potentially a substitute pathway. People with intellectual disabilities who have participated in serious leisure activities, or sporting programmes have been able to develop a higher level of confidence, skills and self-esteem, to engage more in community activities and even enhancing social inclusion for people with intellectual disabilities (Patterson and Pegg, 2009; Thomson et al., 2021). Therefore, although it is not easy to directly empower people with intellectual disabilities to gain more self-governance on their sexuality, we may first consider helping them to participate in activities focusing on their strengths for the enhancement of their self-esteem and the courage to exercise their right in other areas.

For the parent group, the social world is stigmatized by the reduced esteem of a family with a member with intellectual disabilities. The intertwined feelings of anxiety, love and grief associated with social taboos on sexuality mediated the esteem of the family with a child with intellectual disabilities. Therefore, it is crucial to reduce stigma towards family with member with intellectual disabilities. Policy and practitioners should empower the family and enhance public recognition that people with intellectual disabilities are not an eternal child, but a capable, contributing member of society (Vuuren & Adlersey, 2020). At the societal level, evidence-based intervention programmes, for example, with direct contact and familiarity with people with intellectual disabilities, should be promoted (Werner, 2017). Delgado and colleagues (2018) argued that anti-stigma programmes should not only address the more obvious negative reactions towards people with intellectual disabilities but also address affective reactions associated with compassion, as these emotions can perpetuate paternalistic prejudices and the stereotypes of low competence and high sociability. Hence, in addition to the traditional protocol such as activities that jointly engage people with and without a disability, multi-media and internet also play a crucial role in mitigating stigma and changing societal attitudes towards people with intellectual disabilities (Maulik et al., 2017; Maulik et al., 2019). In this regard, perhaps, YouTube's videos may be a good channel to illustrate the true capacity of people with intellectual disabilities or the life story of a family with a member with intellectual disabilities.

For communication on sexuality, caring professionals should increase consciousness of the cultural impact on the family and address carefully the subtle feelings experienced by family members (Govere & Govere, 2016). As noted in the findings (Chapter 8), multi-folded feelings were woven into the fabrics of sexuality of people with intellectual disabilities. Hence,

culturally sensitive communication is important. When discussing culturally sensitive issues like sexuality, practitioners should enhance their awareness and understanding of related concepts. Practitioners should first consider the environment or space in which the conversation is carried out. Practitioners must also keep their eyes open to the embedded linguistic meaning attributed to sexuality. By using culturally sensitive communication, parents and people with intellectual disabilities would feel safe and respected. To have a close and safe rapport, Chinese service recipients are believed to be more active and at ease to engage in the conversation on sexuality (Brooks et al., 2019).

Recommendation for future research

This research covered the tripartite group experience of sexuality of people with intellectual disabilities. Other stakeholders include education, healthcare, and social services for people with intellectual disabilities, however, they have not been involved in the study. The social services staff group was in a tension between a desire to empower people with intellectual disabilities and a need to conform to restriction imposed by agency's hypocritical approach to sex education. But this study did not cover the views of senior management of social services agencies. For future study, it is recommended to involve top management of local NGOs to explore their views and concerns about the sexuality of people with intellectual disabilities. Indeed, intervention programmes are unlikely to achieve their desired aims unless the intervention fits with the skills, beliefs and practices of those responsible for its implementation (Buston et al., 2002). Constant commitment of organizational members and internal stakeholder engagement could enable neutralizing some of the tensions at the organizational level (Sajjad et al., 2020). Without studying the tension between senior management and frontline staff, it is hard to draw a complete picture of the negotiation process on sexuality of people with intellectual disabilities.

To remove barriers on sexuality of people with intellectual disabilities, the provision of training and education on sexuality to schoolteacher should not be ignored. This study, however, did not invite schoolteachers, either in the mainstream or special education sector, to participate. For future study, investigating how educators construct their views of sexuality of people with intellectual disabilities is essential. Further, as shown in this study, restrictive or repressive social norms concerning sexuality influence people's attitude. To make a comprehensive cultural portrait of sexuality, it is also vital to investigate personal perceptions of sex and intimate relationship for staff working in health care, social services, and education sector.

The three groups who participated in this study are independent from each other. It means they either had no blood relationship or were not receiving services from the social services staff. In this regard, the actual negotiation process about sexuality issues among the three groups could not be observed directly. Qualitative research methodologies are inductive and focus on meaning, producing rich and in-depth data, to make sense of the context or phenomena under investigation (Jones & Smith, 2017). By observing actual negotiation process, researchers can have a thorough understanding on the emotional responses and power dynamic of those parties involved in sexuality from an emic perspective. To achieve this purpose, through the application of ethnographic observation, the researcher presents oneself at the scene of people's dialogue on sexuality and investigates the artefacts like meeting notes for case conference or materials for sex education, which might help to produce a fruitful narrative relating to the sexuality of people with intellectual disabilities under Chinese culture.

Strengths and limitations

The pluralistic approach of using of Interpretative Phenomenological Analysis (IPA) and dramaturgy in this study moves beyond description to theorizing and offers the why and how of the experiences related to sexuality of people with intellectual disabilities. In a Chinese socio-cultural milieu, inviting the three groups of participants to talk on the “silenced voices” about sexuality, allowed the researcher to explore how the participants make sense of their experiences. This research acquired the opportunity to examine closely participants’ conceptualizations and perceptions of sexuality and relationship related to their everyday life, and in the working context. Studying the dynamics of people with intellectual disabilities, parents and staff in the area related to sexuality is scarce. The present research is believed to be one of the few existing studies focused on tripartite dynamic within the Chinese socio-cultural environment. It is also believed one of the few existing thesis to offer a sociological perspective of the phenomenon, using sociological lens and theoretical frameworks to explain obstacles about the handling of sexuality of people with intellectual disabilities faced by the participants, and to discover the valuable meanings of the dynamic relationship under the umbrella of Confucianism.

No research is perfect, and this study is no exception. The sample size of this study was relatively small, particularly the group of people with intellectual disabilities. However, it was very difficult to recruit participants for a face-to-face interview during the COVID-19 pandemic. The cross-sectional and convenience sampling design might influence the comprehension of the experience in sexuality among people with intellectual disabilities as well. Moreover, all the participants with intellectual disabilities have a comparatively better functioning capacity, e.g., work and self-care, in which their opinion and experience may not be generalized to other groups of people with intellectual disabilities. All participants of the

parent group were recruited through a parent resource centre in Hong Kong, whose experience, opinion, and attitude, may differ from parents receiving other social services or community linkages. Another key limitation is the gender and role disproportionality. Among seven participants of the parent group, only one father participated in the study. This solitary male perspective limited the views from fathers. Further exploration of fathers' experiences is necessary to broaden the conceptualization on handling sexuality issues among families with a member with intellectual disabilities.

For the social services staff group, participants mainly worked in social welfare services settings; their views could not represent individuals working in special education or other health and medical settings. In addition, neither senior management nor government bureaucrats participated in the study; therefore, the study does not represent perspectives from non-frontline higher management. Further empirical research paying specific attention to the attitudes towards sexuality of senior administration and government officials would help to promote the establishment of a holistic services system that addresses the sexual needs of people with intellectual disabilities on a policy level.

Although the author of this thesis is an experienced counsellor and sex therapist, and consciously used gender-neutral language to talk about sexuality and intimacy, in the context of Chinese communities, female participants may have felt uneasy and inhibited sharing their thoughts with a male interviewer and thus potentially would influence the content and the quality of the data collection.

As mentioned in chapter 4, the author has been socialized to the emic perspective of Confucian, paternalism in family. He has also worked under the social system, and witnessed how the media portrayed sex. This insider's perspective on culture is, perhaps inherently and mistakenly biased with a myopic view towards the understanding of the phenomenon. In addition, as an "insider", the author may not be able to bring a novel perspective in the research process, which may be easily raised by outsiders (Naaek et al., 2011). Lastly, participants of the study may be less willing to reveal sensitive information as if they would disclose to an outsider who is likely to have no future contact with (Holmes, 2020).

Conclusion

This doctoral study has three major phases of enquiry/investigation. Literature review is the foremost task for the first phase. The initial milestone was acknowledging people with intellectual disabilities exhibit the same spectrum of sexual life as the general population: some of them would like not to have sex, while some others enjoy their sexual life. In between the abstinence and having active sexual life, some people with intellectual disabilities experienced regulations around sexuality. These regulations were found to have associations coupled with families and healthcare staff views. These two parties have encountered tensions regarding risk reduction and experienced fear and uncertainty related to sexual expression by people with intellectual disabilities. These fears and uncertainties, eventually, led to the gradual development of the "unintended invisible hand" that imposing regulations on expressing desire in sex and intimate relationship by people with intellectual disabilities. In addition, regarding the attitude towards sexuality of people with intellectual disabilities, the opinions from three groups: public, family of people with intellectual disabilities and health care staff, were reviewed. It was acknowledged that people with intellectual disabilities were not asexual.

However, the public appeared to hold a more accepting attitude, when compared with family of people with intellectual disabilities and health care staff.

The second phase of the work aimed to investigate experiences related to the handling of the sexuality of people with intellectual disabilities. Three groups of participants: social services staff, people with intellectual disabilities and parents, were interviewed. For social services staff, they agreed that all people have the right to have sex and to go on date. Nevertheless, they mentioned the resistance for the promoting the autonomy for sexuality for people with intellectual disabilities from parents and their organization. Under this circumstance, although they disagreed with the situation, they did not protest the restriction.

For people with intellectual disabilities, they have a basic understanding about sexuality and have some dating behaviours with a counterpart without disability. Echo to the phase one findings, people with intellectual disabilities faced the restrictions on sexual expression imposed by parents and staff. However, they did not revolt against the restrictions. For parents, they recognized that sex is a universal human need. Because of love, they would also like to give the best to their child with intellectual disabilities. On the contrary, they insisted on restricting their child with intellectual disabilities, so as they do not enjoy a sexual life and do not have a romantic relationship for fears of having an offspring.

Through the three-party dialogue, all of them were found to have a specific emotion associated to the obstacle and regulation they have faced. For people with intellectual disabilities, they had 'struggle' feeling that referred to an ambivalent situation: they have the desire to have sex and relationship, but they do not give voice to against restrictions imposed

by parents or staff. For parents, they agreed with that people with intellectual disabilities having the right to have sex, but ‘shame’ feelings was identified which acted as a power to make the parents confine the opportunity for their child with intellectual disabilities to develop any relationship. For social services staff, they had ‘resignation’ feelings about the restrictions at personal level. They did not like the situation, but they did not remonstrate against it. In brief, all three parties acknowledged the sexual need of people with intellectual disabilities. Simultaneously, they seemed in a quietism to promote the right of sexuality for people with intellectual disabilities. This “No one take any action” phenomenon, resulted in the work for the third phase of investigation.

Based on the application of IPA, the deeper feelings found in the second stage reflected the lived experience of the individual parties participating in the study. The “all do not take action” phenomenon also reflected a special tripartite dynamic among the participants. The third phase of investigation borrowed the dramaturgical perspective as the theoretical framework to analyse this specific phenomenon. Dramaturgy uses a metaphor that people in the society would stand on a front stage and doing their performance to impress others. One of the strategies to impress others is to avoid embarrassing someone. Based on the concept of dramaturgy, the three parties have formed a tripartite troupe to perform a “Puppetry Front Stage Show”. This puppetry show is an analogy that each party serves as a puppet controlled by the unintended invisible hands. The unintended invisible hands in this metaphor were the puppeteers of the show, which were the four elements of the overarching Chinese values: Sex Culture, *Guanxi* Culture, Filial Piety, and Face culture. The participation of the show eventually helped the social services staff not to be the troublemakers, the people with intellectual disabilities to become a good child, and the parents not to be exposed to conflict and embarrassment in social and family situations. This cultural scene reflected a harmonic and an

equilibristic status among the tripartite troupe, which ultimately were the unconscious acts fulfilling the end goal of the Chinese culture.

The puppet show analogy has no implication on the “puppets” that are merely dolls with no free will. The dramaturgical perspective, instead, asks how people present themselves strongly patterned, or routinized, which are firmly situated within the broader political, economic, social, and cultural contexts (Vannini & Waskuk, 2016). In this thesis, the puppet metaphor revealed the alliance works responding to the cultural expectation and contributing to the creation of an equilibristic and harmonic mutual relational network.

Chapter (Thesis) Concluding Summary

Overall, the aims of this research have been addressed. Based on the pluralistic approach, this doctoral study revealed the tripartite dynamic of three groups of participants: people with intellectual disabilities, parents and social services staff regarding their concern related to sexuality of people with intellectual disabilities. The study resulted in several recommendations to advance the work on promoting sexuality education, research, and social services practice for people with ID. Those recommendations devise new avenues for future study and practice by initiating reform on sex education protocol and raising awareness for communication on sexuality in a Chinese milieu. In closing, the most vital and valuable contribution to the world of knowledge in this study, could be the importance of respecting and recognizing the intertwinement of cultural values and contextual constraints, specifically on the path of observing (or advocating) the sexuality rights of people with intellectual disabilities.

Chapter Ten

Epilogue: self-reflection on my doctoral thesis experience

Self-Reflection

Researcher's personal interests, feelings and experience blended in the first step of a doctoral research that formulated the research topic (Nartey, 2021). As a “banana man”, having yellow skin that is emblematic of the Asian culture, but also having been internalized by the liberal idea from the west, I always have a wish to explore an acculturation phenomenon that melded with oriental dogma and the liberal ideas.

Having a topic, however, is just the direction of a research project. Without a route map, researchers are easily to get lost in the research journey. Literature review is an indispensable and substantive part of a thesis. A thorough and sophisticated literature review is a prerequisite for doing an authentic and refined research. It was the route map that allowed me to situate and to justify the appropriateness of my study, and to develop a theoretical rationale.

There are two literature review chapters in the thesis. In brief, the reviews narrated the experience of people with intellectual disabilities in the area of sexuality, and uncovered that parents and social services personnel were the variables that hindering the actualization of sexuality for people with intellectual disabilities. As a parent with the Chinese background, and with experience in working at the health care and social services sector, I have never met anyone purposely doing anything to be against the wish of people with intellectual disabilities. Both the situations revealed in the literature and personal experience under the same cultural

umbrella inspired me the idea of “unintended invisible hand”, an analogy that describing the dynamic phenomenon experienced by the people with intellectual disabilities, parents, and social services personnels.

Figuratively, double-edged sword refers to a situation that has both good and bad side. On the one hand, sexuality of Chinese people with intellectual disabilities, and their dynamic with parents and the social services personnels are an uncommon topic for researchers to explore. This exceptional situation warranted the significance and value of my study. On the other, there were limited literatures to provide me with the idea for data collection and analysis. To overcome this limitation, my “coping” was to extend my readings to other areas of study, for example, sexuality of people with physical disabilities, parenting and office management in collectivism, dramaturgy in end-of-life care, etc. With English as my second language, academic reading and writing never comes easy. Indeed, I have spent quite a few months in struggling the formation of the conceptual framework for this study.

Bencich et al. (2002) observed that many PhD candidates cannot see the full picture of working out their research, nor it was hard to imagine how they would get to the finishing line, particular at the beginning phase of the PhD study. Hence, sharing opportunities that allow PhD candidates to communicate their experiences to peers during the course of the research journey can be useful to any student. As an international PhD candidate, conducting my research off campus made me difficult to have an opportunity to exchange ideas or share personal struggle with the peers. However, in the “post-COVID” era, zoom meeting is the common practice. A regular online peer sharing sessions might help the future candidates to overcome these difficulties.

The pandemic has created another double-edged sword experience for the research journey. First, the social distancing policy had made the participants recruitment challenging. Wearing mask also influenced the observation of facial expressions of the participants during the face-to-face interview. On the flip side, I finished the first draft of the discussion during the lockdown of my home city. This “confinement” offered me an advantage to focus on my analysis and writing.

Lastly, thanks again to my supervisory panel. Their advice on converting some chapters into peer-reviewed journals articles helped me to develop skills for analysis and academic writing. The feedback I received from journal reviewers had helped me to address the main challenge in the construction of my thesis. Drawing on different opinions from different reviewers gave me clues on which aspects of the approaches I could draw on to further construct my whole thesis, and consider an appealing writing style to engage both lay and expert audiences. I therefore think that it is absolutely a good idea for future doctoral candidates to submit a paper as soon as they get some results and to acquaint to the fear and discouragement of the paper being rejected.

Academic life comprises learning, anticipation, and discovery, but also with ambiguities, worries, and even frustrations. The PhD journey was intellectually challenging, emotionally exhausting and physically demanding. This journey is not merely a test of my intelligence, but also of my resilience, coping, but eventually is a therapeutic process. At the spot closed to the finishing line, I can sense the satisfaction and fulfilment, and the feeling of acquired an academic identity within the scientific community.

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ACKNOWLEDGEMENT EXTERNAL APPROVALS

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