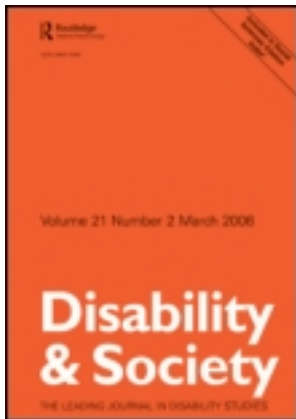


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‘I know that aside from my arms I’m normal’: negotiating the incoherencies of a ‘VACTERL identity’

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VACTERL Association is a medical diagnosis that represents a broad range of characteristics affecting the following body systems: vertebrae; anal; cardiovascular; trachea; esophageal; renal and radial; and limb. Auditory, growth, sex, and reproductive characteristics are often present as well. Thus far, VACTERL has only been examined within the medical system, and, within that framework, it has become identified as an anomaly and ‘disability,’ leaving the embodied experiential realities of individuals who live with it unexplored. This paper reports on a qualitative study with eight self-identified women with VACTERL Association. This paper provides an introduction to the experiences of these women and provides an exploration of the elements and processes of identity negotiation, with particular focus on the intersection between gender and ability. As well, the impact of a medical label as it affects identity formation is examined.

Keywords: identity; disability; gender; VACTERL/VATERS Association

Points of Interest

- This article reports on a qualitative study that explored the experiences of women living with VACTERL Association, a complex and rare medical condition.
- This paper examines the processes and experiences of identity negotiation with particular focus on the intersection of gender and ability.
- Women with VACTERL continuously contend with oppression, which leads to struggle, pain, frustration, and disconnect, all of which becomes central to the process of identity negotiation and formation.
- This paper highlights the ways in which social interactions shape identity; specifically, social norms are transmitted through comments, reactions, responses, jokes, teasing, expectations, and experiences. These values become internalized by women with VACTERL, who therefore identify themselves as having a deviant identity.

Introduction

VACTERL is an acronym used to describe a rare non-random pattern of complex medical characteristics within seven broad categories that are found to occur

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together: V, vertebrae; A, anal; C, cardiovascular; T, trachea; E, esophageal; R, renal and radial; and L, limb. VACTERL is not a concrete diagnosis; rather, each letter of the acronym is used to refer to a broad realm of potential medical issues. The presence of three or more affected systems is required for a diagnosis. VACTERL is sporadic in its nature and varies from person to person (Quan and Smith 1973; Khoury et al. 1983). In addition to this already-broad spectrum, auditory, growth, sex, and reproductive differences are often present in individuals with VACTERL. It is extremely corporal and – although it varies in affected systems, severity, and experience – most individuals go through numerous surgeries, treatments, health maintenance, and ongoing pain. Individuals with VACTERL often become medicalized entities, compartmentalized, separated, divided, and labeled into parts as they are evaluated by a fragmented medical system seeking to cure and fix each individual ‘defect’ (VATER/VACTERL Connection 2007). To date, all discussion and analysis of VACTERL has taken place within the medical framework; one that labels VACTERL as an anomaly, a ‘defect,’ and thus as a ‘disability.’ There has been no discussion or acknowledgment of the personal and social realities involved.

Traditionally, ‘disability’ is a stigmatizing label used to refer to any physical, mental, and/or intellectual ‘impairment’ or ‘handicap,’ any disqualifying deprivation that renders people lacking. The contested label of ‘disability’ is employed throughout this paper to represent, structurally and symbolically, the spaces individuals with VACTERL hold by virtue of their non-conforming bodies.

While individuals with VACTERL may share certain experiences in common with individuals with other medical issues, VACTERL is unique in many aspects; it is statistically rare, there are multiple seemingly unrelated complex affected systems and issues, and there are no clearly delineated perimeters for diagnosis. To complicate the diagnosis, this condition never manifests identically, it is not necessarily clearly hidden or visible, and it is not comprehensively understood. Despite this, the same broad label is used to classify the experiences of those with VACTERL with those who live with other, more common and verifiable disabilities. The very nature of this medical reality often leaves those who live with it feeling isolated, fragmented, and compartmentalized, with seemingly unrelated body parts and systems, in a medical and social system that lacks meaningful understanding about their complicated condition. Examining the experiences of people who live with VACTERL provides a unique opportunity to examine the significance and relevance of the accepted practice of applying broad categorical labels to represent individual experiences and realities. This paper explores the ways in which socially constructed systems of gender and ability influence gender conceptualizations and identity formation for self-identified women with VACTERL Association.

The rarity and complexity of VACTERL has left it experientially and socially hidden, isolated, and silenced. To address this gap, the present study examined the experiences of a group of individuals who have been absent from relevant social research, theory, and models of practice. The purpose of this paper is to deconstruct and thereby introduce identity as it is experienced and negotiated by and for women with VACTERL Association. This paper applies critical theoretical frameworks that seek to examine the nature of structural oppression as it shapes the identities of women’s ‘disabilities,’ and highlights the ways in which language and labels are externally imposed, often becoming central to identity negotiation. Specifically, the nature of social interactions as constructive of ‘difference’ is illuminated, and the inextricable link between gender and ability is explored.

Background

Historically, the experiences of women's bodies have been brought to social attention through the Feminist movement (Wendell 1996). Feminist activists have fought an intense battle for women's liberation, emphasizing traditional gender roles as the cornerstone of identity and site of oppression against women. The ultimate liberation has been believed to be centered on female power, autonomy, control, and freedom from male oppression and violence (Wendell 1996). 'The Female Body' is a socially constructed ideal based on these feminist values. The ideal female body is one of strength, energy, movement, control, and function. This construct demands of women to embody certain looks, actions, movements, and characteristics. Disciplinary techniques and demands for a 'perfect' female body are often internalized and thus shape individual constructs of their own identity (Bartky 1997).

In an effort to draw attention to gender issues and discrimination through deconstructing oppression, the feminist movement operated on assumptions of a supposed universal woman and a single unified movement. Through this process, feminism obscured other intersecting aspects of bodies, experiences, and identities (Garland-Thomson 2001; Wendell 1996). The outcome of the socially constructed 'ideal' or 'norm' is that its demands are unrealistic and unnatural and, as such, construct non-conforming bodies as inferior and 'abnormal' (Bartky 1997; Borbo 1997; Wendell 1996). The myth of the 'norm' is used to identify, define, justify, and maintain a supposed dominant and supposedly natural center of society (Garland-Thomson 2001). The feminist claim that women, as a universalized group, embody strength and independence is a fictitious notion based on body ideals that ignores the realities of bodies that live with physical difference and pain (Wendell 1996), thereby re-victimizing them within feminism as they are within society (Garland-Thomson 2001; Bartky 1997). Such forms of Traditional Feminism have ignored and/or misrepresented the realities and concerns of women with 'disabilities' (Collins and Valentine 2003; Wendell 1996; Barnes, Mercer, and Shakespeare 1999).

Women with 'disabilities' often have a divergent feminist struggle, including the fight against the prevalent stereotypes forced upon them, against the socially accepted stigmas of passive, dependent, asexual, pitiful, heroic, and social burdens, and the fight to be accepted as 'real' women (Lloyd 2001; Kundraat and Nussbaum 2003).

Critical analysis of the ways in which deviant bodies and people with 'disabilities' are oppressed within society has occurred through the Critical Disability Studies (CDS) paradigm. CDS is a body of literature encompassing poststructural and critical frameworks that are utilized to critically examine the individual, institutional, and structural dynamics of Ableism. Ableism is a social norm that determines and defines individuals with 'disabilities' as 'others' who often internalize the oppression and become forced to monitor their own behaviors and actions to ensure that they fulfill social expectations. This point is highlighted by university students in Low (1996) as they discussed the way in which they became forced to confront their 'disabilities' only when they come into contact with the Ableist university system. While there are numerous points of interaction that create and construct individual and group identities, the primary negotiation and interpretation takes place in the interaction between identified 'disabled' and non-'disabled' individuals (Titchkosky 2003).

According to Critical Disability theorists, the accepted social definition of ‘disability’ is founded on the categorization, judgment, and oppression of human differences, and it is thus imperative to deconstruct and challenge common definitions of ‘disability’ as they significantly impact individual and group identities (Davis 2002). Any type of ‘disability’ or bodily difference always signifies a deviance from socially determined standards (Kundrat and Nussbaum 2003; Wendell 1996). Within CDS and other critical theoretical frameworks, ‘disability’ is viewed as a construction of Ableism and therefore as a myth and a fictitious representation of superficial characteristics of bodies based on their similarity or difference from a supposed ‘norm.’

‘Disability’ as a potentially acclaimed inferior identity label becomes negotiated and constructed through society, relationships, and the material environment. CDS provides a basis for challenging the medical model of ‘disability’ that permeates society, and instead examines so-called impairments and ‘disabilities’ as culturally, politically, and socially constructed phenomena. Fundamental to this ideology is the idea that individual bodies, whether fitting in to the ‘norm’ or considered ‘deviant’, are not statistically measurable or able to be generalized. From this perspective, the way in which ‘disability’ is defined, discussed, and represented in society is paramount to the way in which both ‘able-bodied’ and ‘disabled’ individuals learn to construct meaning for and about themselves (Davis 1997; Garland-Thomson 2001). Specifically, stereotypes, labels, and stigma become concretized through interactions with the Ableist world and then become embodied by individuals who live in deviant bodies (Watson 2003; Zitzelsberger 2005). Research points to the ways in which negative social views of different bodies are internalized and become part of identity negotiation and struggle, thereby leading to perceived realities of oppression, dependence, and weakness for women with disabilities (Galvin 2005; Kralik, Toch, and Eastwood 2002; Reeve 2002; Goodley 2003).

Subjectivity, a Foucauldian term, is used seemingly interchangeably with the term ‘identity’ throughout the literature by numerous authors. Both conceptual terms are used to describe the fluidity, complexity, and process of constructing and negotiating personal identity. The authors use the term to illuminate the ways in which identity is constructed through relationships of power and knowledge, as well as the ways in which it deeply influences, and is simultaneously influenced by, relationships, institutions, experiences, discourse, and context (Reeve 2002; Whitney 2006; Kundrat and Nussbaum 2003). Reeve (2002) discusses identity negotiation as a process in which individuals are active constructive agents navigating their own subjectivity and structural oppression. With the emphasis on the subjectivity of identity, the idea of a single ‘disabled’ identity becomes questioned and challenged.

To gain insight into the experiences of oppression on identity construction, it is imperative to explore the ways in which individuals live and navigate social structures. The poststructural paradigm is applied throughout the literature and research as a framework that analyzes and contextualizes ways in which women with ‘disabilities’ live within contested bodies and space, and interpret, negotiate, and internalize the processes, patterns, values, and attitudes of the Ableist world with which they interact (Kralik, Toch, and Eastwood 2002). This approach to identity allows for a very context-specific analysis of the way in which bodies, space, time, and situation become individually paramount in the process of identity formation (Denzin and Lincoln 1998). These critical frameworks have an inherent transformative potential to elucidate the historical foundation of ‘disability’ as it governs, restricts,

and controls the actions and interactions of people with 'disabilities' through systemic medical and social oppression (Denzin and Lincoln 1998).

Wendell (1996) discusses the complexity and challenge inherent in determining to choose, accept, and/or reject an identity label. Specifically, accepting and claiming the label of 'disability' means, essentially, accepting a new identity. This occurs by being forced to alter one's self-perception, to acknowledge real or perceived limits, and to learn to live within an unaccepted, unrecognized body. It is imperative to note that experiences of 'disability' are not fixed and do not occur in a vacuum separate from other aspects of identity. It is clear that identity negotiation is a process in which individuals are active constructive agents navigating their own subjectivity and structural oppression (Reeve 2002). As the research study and selected literature aim to discover the experiences of women with medical conditions, a gendered analysis with an integrated understanding of the multiple and intersecting nature of identities is critical.

Methodology

This research comprised an ethnographic study designed to explore the structural and subjective forces shaping identity negotiation. Online semi-structured qualitative interviews and questionnaires were used as the primary data collection methods. McCracken's (1988) well-established in-depth interview method was used. Research participants were purposely recruited from three virtual VACTERL community forums: the VATER Connection, the VACTERL Network, and Adults with VACTERL. This research was conducted through York University and ethics approval was obtained from the Research Ethics Board at York University. Data were collected in 2007.

Sample

Eight self-identified women with VACTERL Association participated in this study. According to McCracken (1988), a sample of eight has been established to be sufficient in generating theme saturation. Participants ranged in age from 20 to 40, and reside across North America. Participants are English-speaking, Caucasian, and middle class. Amongst them, their life experience, education levels, and occupations varied.

Data analysis

Both deductive and inductive methods of analysis are employed. These two analysis methods took place simultaneously, allowing for a thorough analysis of the interconnections between the micro, mezzo, and macro levels of power, privilege, oppression, and subjective experience (Denzin and Lincoln 1998). NVIVO qualitative analysis software was used. Member checking was utilized as part of the analysis method.

Findings

This study explores the experience of identity negotiation and formation for women living with VACTERL Association. Findings indicate the complexity and intimacy of identity specifically as it is shaped by subjectivity (i.e. a sense of self, strengths, weaknesses, characteristics, experiences, accomplishments, and goals), while structural oppression is enforced through dominant discourse around bodies,

ablebodiedness, 'disability,' gender, the medical system, body control, and reproduction. This study highlights the ways in which personal meaning and socially identified categories are negotiated within the lives of women with VACTERL Association. Specifically, identity comprises a complex and ongoing process of negotiation that is experienced and enacted through social interactions (i.e. language, labels, the physical/spatial environment, reactions, and expectations). Social interactions often create disconnects between subjectivity, an internal sense of self and social location, and an external expression and representation of identity. These external representations are greatly influenced by, and thus reflect, social oppression. This disconnect often results in struggle and pain. Responses include a wide range of strategies that are enacted in different times, situations, and contexts: from silencing the self, grieving, overcompensating, dissociating, self-destructing, and lowering expectations of self, to creating meaning, using experience to help others, investing in alternative places of acceptance and support, working towards self-acceptance, medicalizing/objectifying experiences, and reconceptualizing roles, experiences, and expectations. Although a 'VACTERL Identity' as a subjectively meaningful concept is non-existent, a 'VACTERL' label is often accepted and portrayed as a means of understanding and challenging oppression.

Identity as subjectivity

Every participant is an individual with a particular system of beliefs, values, biases, and subjective medical experiences that situate, shape, and define the way in which VACTERL Association is internalized as part of identity. The obvious yet profound knowledge of identity as subjectivity is made explicit through participants' articulation of their sense of self. Notably, prior to discussing the specific nature of their medical diagnosis, participants speak of their individuality and uniqueness as integral to their identities, and seem unconcerned with and disconnected from overarching diagnostic labels and categories. For example:

I'm strong, I'm an individual . . . I'm smart, and work hard, I'm caring and like to be around people, I like making friends.

Through many narratives, participants speak of how the diagnosed issues, pain, and 'anomalies' are assimilated into their subjective identities and, accordingly, become 'normal' and unremarkable. Women with VACTERL contend with numerous medical issues. For example:

. . . and my main one was the Anal stuff – I had an anal pull through, hysterectomy, vaginal reconstruction when I was 17, and I did an enema twice daily (still do), plus now wear a stent to keep my vaginal canal open . . . so it was super private and I didn't and couldn't share that much.

Contending with numerous medical issues, identity synthesis often rests in uncovering the significance of their bodies and corporeal limitations.

The absence of social interactions, oppression, and stigma in many participants' initial articulation of their identities shines light onto a specific reality; although prevalent and significant in shaping individual identities, identity is subjectivity, it is self, it is something intimate and personal, not a category or label forced onto one by others.

Identity negotiated through interaction

Labels, language and meaning

Regardless of personal power, experience, and choice, through participants' narratives, it is evident that the weight of stigmatizing labels such as 'disability,' 'handicap,' and 'abnormal' are negotiated into self-concept. Specifically, the internalization of oppression, as experienced through social stigma, judgment, and discrimination, was prominent in participants' identity construction and negotiation. The following examples shed light on this point:

Like family, best friends, boyfriend ... they treat me like a normal person ... they've always treated me like any other kid.

There are days when I would give anything to be 'normal' and there are other days that I can accept myself just as I am.

No one can tell just by looking at me that I have anything wrong – I look normal from the outside ... I just want to be normal and fit in.

Only because I think it's too cliché to identify myself as a disabled person ... I've had a difficult time accepting what my disability meant on the large scale.

Gender

Although all participants identified themselves as women, through their discussions it became clear that this label did not represent their realities consistently, and that they chose this label because there are no other gender labels from which to choose. For example:

I have trouble with this [defining womanhood], and know that whatever its definition is, it does not apply to me. Because I am not exactly a woman nor do I aspire to meet the criteria to be *their* equal.

One of the central aspects of identity negotiation is understanding, reconciling, and recreating gender identity. Participants expressed recognition that 'normal' gender is a privileged and essential status that represents social ideals and values. They identified three main criteria for a normative gender identity: sexual and reproductive organs, appearance, and performance. Within the confines of traditional gender definitions and social expectations of a normative body, participants classified their gender identities, as 'different' and thus, inherently abnormal and inferior.

Sex and reproduction. Participants identified biological makeup as a central determinant of gender and cited their sexual and reproductive differences as the primary aspect of VACTERL that denounced them as not being 'real women.' They discussed in detail the ways in which this value is transmitted, internalized, and affects their identities. To these participants, being considered a 'real woman' in society requires not only being born with standard reproductive and sexual organs, but that those organs must function to a set standard. Accordingly, 'real women' are born with a vagina, uterus, two ovaries, functional sexual organs, and the ability to procreate naturally. While individual bodies differ and there is no single biological impact of the VACTERL diagnosis, many women with VACTERL are born with

variations of sexual and reproductive organs and capacities. These socially-labeled deficiencies are either inborn traits or results of medical interventions. For example, many participants were born with medically labeled as sexual and uterine ‘anomalies,’ which includes no uterus, double uterus, double no vagina, vagina and cervix, no ovaries or detached ovaries. Functional capabilities varied as well. Additionally, medical complexities, such as heart failure, have interfered with some participants’ ability to carry a pregnancy.

Living with complex reproductive realities, participants concluded overall that without the required sexual organs they had no right to claim the status of ‘real women.’ The experience of facing an ‘abnormal’ sexual and reproductive reality was often identified as a process of pain, loss, and grief. One participant discussed her experience: ‘When I found out I couldn’t get pregnant that was a big part of the female process that I did grieve the loss of.’

Being unable to comply with these socially-constructed demands has led many participants to reexamine their bodies and redefine standard definitions of gender to represent their personal and medical realities. Specifically, many participants discussed their alternative paths to sex (i.e. vaginoplasty, vaginal stent, dilatations) and reproduction (surrogacy, adoption, living vicariously through friends’ experiences). Although alternative sexual and reproductive means are often necessary and/or chosen, traditional means are always perceived by society as being the ‘normal’ way.

Appearance. As a medical diagnosis, VACTERL is not positioned as being automatically incongruous with womanhood; rather, it is often the visible differences that are signify deviance. The visible markers of VACTERL, the ones that are *not* the most medically complicated or painful, are the ones that are given the most social weight. Traditional beauty norms and expectations play a strong role in participants’ understanding of their own bodies and construction of their identities.

Through interactions with family, friends, strangers, the healthcare system, and other social systems, participants have learned to recognize the high social value placed on physical presentation. The visible differences are the ones that are often valued, objectified, and judged by others and, thus, by the individuals living with them as well. Inability to measure up to social expectations, as well as lifelong incidents of rejection and isolation strongly, influence their subjective experiences of their medical and physical realities. It is external representations of self that fundamentally differentiate the ‘normal’ from the ‘abnormal.’ Participants posited many aspects of their bodies as being inherently ‘abnormal,’ ugly, and in complete opposition to demands of femininity. To cite some examples:

They are only interested in the fact that my hands are different, and act as if I’m complaining about a lot of nothing. I’ll mention being too sick from intestinal problems, and they say everyone has to use the bathroom. I get made fun of for accidents. I do not think my body is attractive at all. Aside from just that, I find myself very unappealing. I still look disgusting to myself, between scars and asymmetrical body parts, I’m pretty backwards looking ... they [society] would always prefer normalcy and perfection over distortion.

I don’t even fit into the ideal image, not even close. I’m short, I have a severe curve, in my back, I am missing my left thumb and radial bone, so my hand is ugly ...

Through such narratives, it became evident that the notion of VACTERL bodies being ‘different’ bodies surfaces primarily when they become visible to others and

are publicly dissected and analyzed. Appearance was cited as one of the most challenging and painful aspects of gender identity because it is something that, when deviant, becomes hypervisible and a source of tremendous pain. When the visibility of VACTERL disappears from public view, 'difference' diminishes as well. Participants discussed their desire to achieve the superficial demands for beauty and appearance and the numerous ways through which they tried to hide their physical differences to allow them to pass as 'normal,' something some women with VACTERL covet:

My arms are a symbol of everything. I feel that others are luckier than me because they can hide it . . . where I have no choice. We work with our hands . . . I know it's not a right perspective, but I get ashamed of my appearance, though I know aside from my arms, I'm normal . . .

While acknowledging that society's construction of femininity is superficial, narrow, and limiting, many participants experience pain, frustration, and struggle as they work to understand their physical bodies and fit in to that same ideal that they acknowledged as unrealistic. Referring to the visible aspects of VACTERL, one participant concluded: 'It [VACTERL] is sadness in a world that covets perfection.'

Performance. Identity often evolves through an individual's inability to measure up to performance standards. Physical, emotional, and mental strength were cited as important characteristics of 'normal' gender, and therefore ones that many participants want to claim and embody.

Medical complications, physical differences, pain, stress, and bodily demands have made it impossible for some participants to perform up to social standards. Everyday activities, from buttoning shirts and tying garbage bags to social activities, can be problematic and challenging. One participant stated: 'I manipulate my arms in ways they don't bend to achieve daily tasks, such as buttoning some jeans or using a can opener.' Confronting the 'norm' in this way on a continuous basis has made it difficult for these women to conceptualize these barriers as anything but internal deficiencies. As one participant asserted:

It's [VACTERL Association] the last thing I think of when I'm working . . . Until I can't get a tube of paint open, then I curse my hands of course.

Many participants discussed having difficulty keeping up physically with others and the ways in which it reinforced feelings of otherness. For example:

I don't like being a limitation like when I'm out with people, I try and stay up with them and don't like having them slow down for me, no matter what . . . but sometimes I just can't do what everyone else is doing . . . when I can't do something that other people are doing, people my age, then I feel different.

Living with VACTERL often entails continuous and immediate attention to health issues and body needs. Many participants expressed feeling alienated from their peers who were busy with 'normal' activities like cheerleading and romantic relationships. Instead of being able to partake in common social activities, for many participants, activities often revolved around their bodily needs such as bowel and bladder management regimes, medical appointments, and acute or chronic complications.

Identified by participants as ‘potty issues,’ a lack of bowel and bladder control has played a significant role in identity construction for women with VACTERL. Specifically, anal and bladder malformations have resulted in many women with VACTERL having limited or no control of their waste management systems. A lack of bowel and/or bladder control often causes acute embarrassment and shamefully separates many with VACTERL into a category of ‘abnormal.’ Through knocks on bathroom doors, stares, comments, and dirty looks, such ‘differences’ are continuously reinforced as unacceptable and ‘gross’ by society. Potty issues, something they actively try to control, are viewed by participants as inherently incompatible with standard measures of femininity, and as one of the most difficult aspects of VACTERL to confront and reconcile:

Having limited bowel and bladder control impedes all of my daily activities. I have to stay close to a washroom, watch what I eat and drink so I can avoid ‘accidents.’ My back is always sore and I limp sometimes and this inability to hide my condition can be upsetting. My partner has been very understanding and accepting of me, but I still find the VACTERL gets in the way of our relationship. It affects our sex life, my ability to trust him and be completely open with him and enjoy activities that other couples can participate in freely. At work, I have to take frequent washroom breaks and some employers and coworkers have not been understanding. The same experience has followed me at school ... There is heaviness in my heart that won’t dissipate. I am screaming inside because this body of mine has caused so much pain, so much humiliation, and there is nothing I can do to change it. It is so hard to not have full control of your body, to be subject to painful medical exams and treatments, to be misunderstood. Sometimes I feel betrayed by my body.

Participants discussed how they have been able to maintain the identity of ‘woman’ and the image of femininity only by actively dissociating from aspects of VACTERL that could not be reconciled with social standards:

The potty part isn’t feminine, it isn’t even something that a child past three should deal with – I didn’t want to be the girl that still craps in her pants ... I try not to let that be a part of my self-image.

When explaining the reason for hiding her incontinence, one participant illuminated the ways in which bodily issues are valued and judged differently and the ways in which her actions and behavior are modified accordingly:

I don’t feel discomfort/embarrassment with any other part of VACTERL – everything else set me apart from the crowd – they are what impressed people ... The first time I went to school I realized that people could see that I had pooped in my pants and asked me about it ... that’s when I learned to lie. That’s when I knew this was something I wanted to hide – that it made me feel different in a way that I didn’t want to be.

High demands are placed on women to perform at home and at work, in private and in public. Inability to perform to normative standards constructs feelings of otherness and deviance from the norm. In efforts to claim a female identity, to be considered women by themselves and society, women with VACTERL make efforts to create socially acceptable public display.

A 'VACTERL identity'?

Regardless of the degree of identification with stigmatizing identifying labels such as 'disability,' 'handicap,' and 'abnormal,' all participants have ascribed to VACTERL as a concrete status at some point by identifying themselves as people 'with VACTERL.' There is very little commonality amongst these women with relation to the specific medical aspects of VACTERL Association. Even when living with the same acronymic letter, the specific experience and medical significance of it varies. Living with VACTERL Association is living with a medical condition that is widely unknown and that is neither concrete nor stable. The 'VACTERL Identity' was adopted and presented by participants primarily for the label as it allowed them to connect with others with the same condition. This identity label is important as it allows for individuals to connect with others who understand the corporeal experience of VACTERL, namely physical and medical experiences and pain. Participants highlight the value of connecting with others with VACTERL:

I have only recently begun to connect with others, but it is so relieving to be able to share my experiences with others that have a first-hand knowledge of the condition. Unless you have gone through it, you truly cannot understand the challenges of this condition.

In conceptualizing themselves as different from the rest of the able-bodied world, many participants ascribed to the diagnosis as it automatically constructs for them a space that is their own, one that contextualizes and normalizes their 'innate' differences. For these reasons, participants appreciated the commonalities of the VACTERL realities that isolated them from the rest of society. Critical analysis of the narratives of the participants highlights that the primary commonality, and therefore the purpose in ascribing to a VACTERL label, rests primarily in the comfort of validation around experiences of marginalization and oppression. According to one participant, a VACTERL identity is about 'Being odd and different than others, being judged and humiliated.'

It is due to such reactions that embodying VACTERL Association as an identity category has become meaningful, powerful, and necessary. It provides the opportunity for members to connect, share, and collaborate on common issues and concerns while creating a space in which deviance is normalized and counters experiences of oppression, discrimination, and isolation. Significantly, participants internalized and embodied the label of a VACTERL diagnosis in ways that illuminate the complexity of identity and its inability to be captured through language. Pointedly, participants defined and internalized the medical aspects *only* as they impacted their lives; official medical terms for the condition were often absent, discussed as an external construct seemingly beyond individual reality. Participants' narratives indicate that identity is subjective and that commonality is primarily oppression and marginalization.

Discussion

The narratives of women with VACTERL Association shed light on the fluidity and complexity of identity synthesis. Notably, the challenge of synthesizing identity lies in the dissonance between the internal and external, between the individual's intimate experiences and knowledge of self that constantly clash with social expectations.

Throughout the narratives of women with VACTERL Association, identity is seen as something highly unique, subjective, contextual, and multifaceted, a holistic descriptor of self. However, internal self-awareness and subjective identity are greatly influenced by social values and oppressive constructs. Despite their subjectivity, women with VACTERL Association internalize and often present a deviant identity. They are forced to compensate and negotiate their identities around oppressive assumptions and judgments about their bodies, abilities, and capabilities. Through encounters with individuals and systems, women with VACTERL Association collide with the ‘able-bodied’ and learn that, as ‘normal’ is an inherent and concrete status based on normative blueprints, their bodies are deemed deviant. These social interactions concretize body politics, through which VACTERL Association becomes an inherently ‘different’ bodily identity.

Women with VACTERL continuously internally and/or externally battle for their rights to experience ‘normal’ identity. Internalizing oppressive judgments, such women are forced to continuously prove themselves to the dominant able-bodied world as competent and worthy, justifying and silencing the specific aspects of themselves that do not fit. Through social interactions these women learn the sexual, reproductive, appearance, and performance expectations of ‘real women,’ an identity they cannot claim. Through stares, comments, and questions, women with VACTERL learn how to dress, how to act, and the socially appropriate way to speak about their bodies. Complying with expected behavior is socially rewarded; defiance is met with punishment. Women learn to interpret their own bodies through other people’s attitudes and reactions. Most often, medical issues became embodied negatively and as inherently ‘different’ *only* when individuals confront these social and ideological barriers.

The opposite holds strong as well; medical issues become interpreted uniquely, often as symbolic of strength, when individuals are surrounded by support and respect. An ongoing process of interpretation, synthesis, acceptance and/or rejection of each aspect of identity is prevalent in the lives of women with VACTERL who seek to create acceptable gender identities.

The experiences of women with VACTERL highlight the ways in which the ‘norms’ governing identity categories are socially created and dependent on context. Specifically, the concepts of ‘woman’ and ‘disability’ as categorically superficial is emphasized through participants’ elucidation of their ability to ‘pass’ as real women when scars and other body markers are publicly invisible. When able to fit in with the ‘norm’ in terms of physical appearance and performed activities, claiming a normal identity is possible. When the social expectations governing appearance and performance are minimized or pushed aside through accommodating physical, environmental, social, and emotional spaces, women with VACTERL Association are allowed the opportunity to be ‘normal’ women:

VACTERL Association . . . means that I’m different and have limitations, but sometimes I forget how different I am, like when I’m with friends who don’t treat me differently, because we don’t talk about it, or we don’t even notice it, we just are ‘normal’ together.

As one participant explained:

In Western society there is an intense focus on perfection, on smooth skin and perfect proportions, an ideal that so few can reach. Ideally, I think society expects a woman’s body is made to fulfill sexual needs, to procreate, to age but maintain optimal beauty

and performance. I have always felt extremely inadequate ... for years I have been ashamed of my body, its flaws, its shortcomings ... I will never fit in to that model of perfection that society projects and it truly breaks my heart.

Another participant acknowledged the ways in she internalized these social norms:

I tend to paint beautiful slender women, and enjoy when I can depict her with a very sensual appeal. It's messed up, because I don't mean to promote that trend, but I agree, she's most beautiful perfect. I hated myself. I was suicidal those 11 years. I began to connect with mutilation and dreaming of doing messed up things likes severing my arms as a statement.

Tremendous individual agency and power is involved in constructing identity; a process of synthesizing biomedical, physical, emotional, experiential, and personal aspects of self. Pathologizing individuals leads to the delegitimization of individual subjective realities. Identity formation is often difficult for women with VACTERL Association, as they cannot find space in which to reconcile their own experience and knowledge of their bodies with broad social definitions and expectations. While acknowledging that societal expectations are largely superficial in their constructions of a supposed female body, many expressed pain, frustration, and a lifelong struggle in trying reconcile their gender identities. The battle individuals face in trying to fit in and live up to socially imposed and legitimizing identities demands creative solutions to the holistically defining constructs that attempt to capture lived experiences. Prior to using labels and categorically defining others, it is imperative to recognize the personal and political meaning each label holds in both constituting and representing identity. This paper brings to light the voices of individuals living with VACTERL Association that have thus far been silenced.

Limitations

This research provides insight into the nature of identity as embodied by women who live with VACTERL Association. Although saturation was achieved, the sample size was small, limiting the generalizability of the findings. Additionally, there are significant structural and geographical limitations to the research methodology employed. This research is conducted virtually and in English, narrowing down the opportunities for participation (i.e. due to economic factors, typing capacity, physical strength, and fluency in virtual communication). For the purposes of this project, self-identifying women were interviewed and individuals self-identifying with other gender categories are absent from this research. As the focus of the research was on the ways in which gender and ability are experienced by women with VACTERL, other intersecting aspects of identity (e.g. race, ethnicity, sexuality) were not critically examined. This is a significant limitation and should be addressed by future research.

Future Research

More expansive research exploring the experiences of all individuals with their varying forms of VACTERL would be beneficial. Future research should take shape through more postmodern methodologies to explore identity as holistically captured by those who live it without being bound by identifying labels.

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