

'My mom was my left arm': The lived experience of ableism for girls with Spina Bifida

ABSTRACT

In many cultures, people deemed different, deficient or of lesser value are socially marginalized, disempowered, devalued and face innumerable barriers to health and quality of life. Persons deemed dis-abled are one such group. Through oppression, discrimination, and constant degradation, marginalized groups are denied the basic human right of dignity. For five girls with Spina Bifida, the experience of societal ableism, i.e. the belief that being able bodied is normal, eroded their sense of self worth, impinged upon their human rights, and isolated them in their own degradation – until they came together and spoke.

'My Mom Was My Left Arm' illuminates the impact of ableism on the health and well-being of girls living with Spina Bifida. Several focus groups with five girls concerning their lives, anger and health yielded compelling reasons for today's contemporary nurse to explicitly practice from a social justice framework. In being deemed other, less than and viewed as their disability, the young women interviewed believed they had never reached their actual life potential. The relationship between health and ableist discrimination as lived by young women with Spina Bifida will be explored. The paper will close with nursing's ethical imperative to advocate for social justice, equity, fairness and dignity.

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hand delicate and destructible, on the other miraculously tough and resilient, and capable of striking back in unexpected ways. By acquiescing in an act that can cause such suffering to a living creature, who among us is not diminished as a human being?

Rachel Carson (1962: 100, 192)

PROLOGUE

The 'control of nature' is a phrase conceived in arrogance, born of the Neanderthal age of biology and philosophy, when it was supposed that nature exists for the convenience of man. As crude a weapon as the cave man's club, the chemical barrage has been hurled against the fabric of life – a fabric on the one

It may appear odd that an article setting out to illuminate young women's lived experience of ableism starts with a quote by an ecologist. It was a blisteringly hot June afternoon in 2003 when I was reading Rachel Carson's 1962 book *Silent Spring* while in transit to a meeting with a

group of young women living with Spina Bifida. Carson warned of a blind faith in toxic elixirs that would somehow control nature and weed out the unwanted, undesirable plants and wildlife. Despite both her credibility and her sanity being viciously questioned by pesticide companies, she refused to stop making connections between greed, hierarchy and the degradation of the earth and its inhabitants. I became awestruck by the fact that it was not a typical spring; that instead, we were experiencing an August heat wave in June. I found myself making profound connections between the group of young women I was about to re-convene, their lived experience of oppression as previously told to me, and the oppression and exploitation of the natural environment. I began to think that the ideologies of greed, power and societal hierarchy that authorize injustices based on gender, race, class, sexual orientation and, in this case, ability, were the same ideologies that sanctioned the exploitation and degradation of the environment. I am convinced that mankind's erroneous belief, that power and control are essential to maintain order, is the same belief that fuels the oppression and exploitation of animate and inanimate nature, and devalues some groups of people.

Native American chief Sealth (Seattle) said over 150 years ago (emphasis added):

Teach your children what we have taught our children, the earth is our mother ... This we know. The earth does not belong to humans; humans belong to the earth. This we know. *All things are connected* like the blood which unites one family ... Whatever befalls the earth befalls the children of the earth. People did not weave the web of life, they are merely a strand of it. Whatever they do to the web, they do to themselves.

INTRODUCTION

While conducting a large qualitative study exploring the lived experience of anger in the lives of various girls and young women, I

had the privilege of meeting with a group of young women living with Spina Bifida (van Daalen-Smith 2004). In several focus groups we discussed specific questions pertaining to their lived experience of anger. I was delighted when the spokesperson for the group called me between our scheduled focus groups. The girls wanted to experience again the camaraderie they felt by coming together to talk, affirm one another and speak about their lives from a position of authority. This I knew was emancipatory nursing and emancipatory research.

While the core findings of the young women and anger study will not be discussed here, this paper discusses how the experience of being marginalized and pathologized generated anger and impinged upon health and quality-of-life for young women deemed *disabled* by mainstream culture. My use of the terms ableism and disability is anything but apolitical. For the purpose of this paper, ableism is defined as:

... the pervasive system of discrimination and exclusion that oppresses people who have mental, emotional and physical disabilities. Deeply rooted beliefs about health, productivity, beauty and the value of human life, perpetuated by the public and private media, combine to create an environment that is often hostile to those whose physical, emotional, cognitive or sensory abilities fall outside the scope of what is currently defined as socially acceptable. Ableism or disability oppression reflects the viewpoint that people with disabilities or limitations are considered to be inadequate in meeting expected social and economic roles.

(Rauscher & McClintock 1997: 198–199)

Further, the term 'disability' or 'disabled' in the context of this commentary embraces the notion that 'a person or a group of persons are disabled by unnecessary social, economic and environmental barriers more than by a physical, psychological or developmental condition' (ibid:

200). Lastly, this commentary uses *people-first* language and invites its readers to understand the enormous difference between labeling the girls in this study Spina Bifidics rather than girls living with Spina Bifida.

VIEWING HEALTH UPSTREAM

*Health is the increased becoming of
who we are most deeply.*

(Anonymous)

It is important to properly situate how ableism impinges upon health and, to do this, one must understand health in its broadest of conceptualizations. Feminist health activist Helen Levine (1989: 247–8) states:

... the helping professions have historically located the key source of most personal pain and trouble within the individual and, accordingly, the emphasis in practice, regardless of intention, is focused upon individual pathology, deficits of personality and ultimately upon adjustment at the personal level.

As a feminist nurse, I have often found myself inviting colleagues, students, mental health professionals, policy makers and laypersons to look beyond the individual and to consider the structural hierarchies at play that disadvantage some groups while advantaging others. Butterfield (1990) calls this *upstream thinking* and urges nurses to explore both the determinants of, and structural barriers to, the health of individuals and aggregates. Viewing health upstream focuses on the factors that erode health and quality of life, rather than solely working on the outcome of systemic barriers to health alone. Upstream thinking requires a paradigm shift that understands health as political, that is, that the personal is political. From the narratives of these young women living with Spina Bifida I am convinced of this more than ever. For the context of this discussion, ableism, discrimination, indifference, intolerance and viewing the disabled as an inconvenience are key upstream factors that impinge upon the health of girls with Spina Bifi-

da. To truly understand the lived experience of these young women, nurses *must* understand their lived experience of ableism, and understand nursing as an act of emancipation.

Situating this commentary

The author's doctoral dissertation was a feminist qualitative research study which explored the lived experience of anger for 65 diverse girls and young women. Nine sets of focus groups, including a series of focus groups with girls living with Spina Bifida were held wherein girls were asked to describe their experience of anger. Focus groups and one to one interviews yielded rich data, which was then coded using Lincoln and Guba's (1985) 'Constant Comparison' method. The data were divided into manageable portions called 'bibbits', which were then coded to identify story lines (Chenitz & Swanson 1986). The Relationships between coded data was explored, yielding amongst other things a relationship between societal stigma, oppression and anger. The transcripts from the focus groups with young women living with Spina Bifida were remarkable because of the rich description of anger linked with their treatment by the health care system, the education system, and by society in general. As a nurse researcher, my ontological leanings celebrate the value of personal description as a way of coming to know, and for this reason, the focus groups with the girls with Spina Bifida were analyzed separately using the same process described above in order to identify the themes that are to be reported here.

Ethical considerations

A research protocol was submitted to the Education Ethics Review Committee of the University of Toronto, and written approval to proceed was granted. As a nurse researcher, I am responsible for 'safeguarding the trust of the participants that information learned in the context of the research relationship is protected' through anonymity measures (CNA 2002). Measures to

ensure confidentiality were outlined in the research protocol submitted to the EERC of the University of Toronto. As well, safeguards to ensure participant safety, choice, confidentiality, and respect, were explained and approved prior to any field consultations, interviews or focus group convening. In this study participants, and their parents/guardians where applicable (for those under the age of 16) were provided with a detailed informed consent which outlined these concepts as well as the intent of the study. The young women who participated in this portion of the study were involved with a provincial Spina Bifida Association, and administrative, parental and participant consent was obtained. All identifiable information, such as the audio tapes and verbatim transcripts, were coded to protect the participant's anonymity. Care has also been taken to ensure the anonymity of the participants. The overriding ethical principles guiding this nursing research are those found in the Canadian Nurses Association Code of Ethics (2002) – choice, respect, dignity, fairness, accountability and confidentiality. All participants had as much information up front including the interview and/or focus group questions before they agreed to participate. In addition, all were afforded the right to withdraw at any time and to remove or adapt their contributions. Munhall (1988) discussed qualitative research as a moral as well as a knowledge-generating activity whereby consent should be viewed as an ongoing transactional process:

Perhaps the most critical, ethical obligation that qualitative nurse researchers have is to describe the experiences of others in the most faithful way possible. The ethical obligation is to describe and report in the most authentic manner possible the experience that unfolds even it is contrary to your aims.

(Munhall 1988: 153)

Of utmost importance was protection of the participants' dignity, not only in the time they

spent in dialogue with me either alone or in a focus group. Close attention was paid to enacting a communication style and constructing a climate of respect that ensured that their views and their perceptions were never dismissed, trivialized or pathologized by myself or other participants.

Understanding lived ableism: The lived experience of young women with Spina Bifida

Women have often felt insane when cleaving to the truth of our experience. Our future depends on the sanity of each of us, and we have a profound stake, beyond the personal, in the project of describing our reality as candidly and fully as we can to each other.

(Rich 1979: 190)

I felt honored as a feminist nurse researcher to have convened a group that overtly articulated feelings of emancipation and empowerment subsequent to meeting with me. They wanted additional meetings – outside of the meetings we had already scheduled. In our initial conversations about anger, perhaps in those brief hours we shared, they had their anger affirmed and were now ready to discuss life as being seen as their disability. Their request moved me into deep reflection. For several weeks, I began to consider the role of denied rights in the quality-of-life of girls and young women. In recalling these thoughts, I decided to invite dialogue about the *United Nations Convention on the Rights of the Child* (1986) (UNCRC). As a recent nurse-appointee to the Canadian Coalition for the Rights of Children, I was more convinced than ever that the UNCRC truly was *the* tool of the millennium for contemporary nurses. This conviction fueled the discussions I was privileged to convene.

In my time with the young women associated with the Spina Bifida and Hydrocephalus Association of Ontario (SBHAO), I learned so much from them, and they from one another. I learned that, as young women with disabilities, they

have ‘disability specific incidences of anger’ (Christine, age 24). One young woman who does peer counseling told me that most of her counseling for adults living with SB is related to anger issues, because of memories of poor treatment and also because they are at a significantly higher risk for being more socially isolated and therefore having no one to support them through hard times so ‘things build up’:

Many adults with sbhao can remember things such as being paraded naked in front of medical professionals in auditorium-type settings, painful medical procedures being done without explanation, compassion, support systems present or informed consent. *Christine*

In asking about anger, I learned of their experience of being marginalized. They were always made to feel different, and had to tell their story over and over to able-bodied people. They felt excluded most times and live their life as a constant struggle. They expressed anger about being made to own their disability, that they were often seen as an inconvenience or something on display. The attitudes of others, especially in school, created a barrier to their learning and they consequently felt that they had never reached their full potential. Having a disability, for some, meant that they were seen as stupid, asexual, an inconvenience, and not a full person.

The group was thrilled to meet again and, after we shared a meal and spirited conversation, we were excited to enter into a dialogue pertaining to child rights. Each young woman was provided with the UNCRC in the form of a *kid-friendly* poster – a poster with the rights of children written by children and young persons themselves. They each received a set of 54 green 2 x 3-inch cards with one article written on each card. Their task was to explore each card and refer to the kid-friendly poster in order to fully understand each of the rights. I asked them to decide privately if any of those rights had been violated in their own lives. Then I asked

them to take those particular cards and form one pile. A second pile was to be made of cards with rights denied to young women with disabilities generally. A third pile was made of those rights that were not applicable.

I asked the young women, when they were ready, to choose the right that was most pertinent to their lives. They were invited to share only to the degree that they felt safe and comfortable. Joan told a spirited story of disgust related to Article 17, ‘Access to Appropriate Information’:

I have a bladder-control problem, and there’s a TV commercial that really bothers me. There’s a little kid speaking of his problem saying he needs a diaper or a pad or something, and how all the kids make fun of him, and now with this pad he is considered ‘normal.’ The media delivers a harmful message to kids about what is normal and what is not. Once I had a classmate tell everyone that I wore a diaper. It was made into such a big thing. *Joan*

Linda chose Article 3, ‘The Best Interest of the Child’. She told how after her parents separated, her father moved to several inaccessible places. ‘If he was thinking in my best interest he would have chosen places that were accessible. Sure, he carried me and didn’t mind a bit, but I did.’

Melissa said that many of the articles related to her in some way, but the ‘one that caught’ her was Article 12, ‘The Right to an Opinion’. Melissa told us that her opinion had never been taken seriously, ‘not in school, in the community, nowhere. Due to being a youth, I think. Doctors always talk to parents, not me. “Hello! I’m here! I’m in the room.”’

By inviting dialogue about rights we shared narratives that, for the most part, had never been shared before. As we listened to experiences of being marginalized, commonalities emerged. One example of a commonality was the experience of being made to feel different

and constantly having to tell their story to able-bodied people. Linda, Melissa and Joan were each ‘the only disabled kids’ in their schools:

I was so inferior. I was isolated totally so I had to eventually go in front of the whole school and tell them that I was just fine and just had a ‘different look.’ I was the first-ever disabled student. *Melissa*

Carolyn described what she called her last straw as it pertained to the violence and abuse experienced by many young women with disabilities:

The grade-six class waited for me when I was in grade four. I was invited by one of them into the bathroom and they beat the hell out of me. The principal said: ‘I can’t suspend the entire sixth-grade class, so I’m suspending you.’ That was the last straw. I left the school and went elsewhere. *Carolyn*

The girls consistently felt excluded and experienced life as a constant struggle:

All through grade school, all the outings, field trips and gym classes I was excluded from. I couldn’t participate in them. I was the only kid with a disability in the school and so I was kind of set aside from everything else. The teachers said: ‘Oh well.’ This affected me for a long time. It’s what I remember most about grade school. *Joan*

Melissa said, ‘I couldn’t make friends, I was so busy explaining and fighting.’ The young woman described the continual expectation of able-bodied persons that they ‘own their disability,’ and learn to cope. Jessie, who requires a powered wheelchair, shared a story of being seen as an inconvenience; and Linda described one of many experiences of being ‘on display’ and feeling ‘like a freak.’ I was told: ‘Don’t scratch the doors as you go by.’ Linda offered the following:

I was the only person with a physical disability ... the only person in a chair. There were ramps and we had this thing, I can’t call

it a machine, a stair-track pulley-thing that pulled you up the stairs. Thump! Thump! Thump! It was freaky and I never forgot it. Sometimes I’d be leaned back in it and I was so scared – and totally embarrassed. When I was in grade school the building was totally inaccessible. They were going to get an elevator but ‘there was no money,’ you know? All the kids blamed me when our class was moved into a portable.

The negative attitudes of others, especially in school, created a barrier to learning and consequently the girls said they felt that they never reached their full potential.

Linda said, ‘We had a special-ed class where I would go. In high school I got more one-on-one and teachers in classes with me, but in elementary school that wasn’t there. There was inadequate support.’ And Melissa explained:

I needed extra time. I needed computer access and didn’t get it until grade 11. I always had to tell everyone all about my disability. I couldn’t climb the stairs very fast and they didn’t understand it. The bell would ring. I’d walk the stairs and I’d be late. The teacher would always say: ‘You’re late. Why are you late?’ I’d always have to explain that it takes me a long time to walk up the stairs and they’d still mark me late ... There was also no elevator in the school. ‘No money,’ they’d say. ‘No funds.’

Being seen *as* their disability meant the young women were thought to be stupid, seen as an inconvenience, and not as full persons. Melissa spoke of constantly needing to prove that just because one of her arms was *abnormal* and could not be used for typical activities, or because she walked ‘differently’, didn’t mean she was stupid. She recounted numerous examples of being silenced or dismissed because of her disability and because of her ‘abnormal’ left arm, and that her mom often had to be her strength and her voice:

My mom was my saviour. My mom was my left arm. *Melissa*

THEIR 'LIGHT-BULB MOMENT': UNDERSTANDING LIVED ABLEISM AS A BREACH OF CHILD RIGHTS

I then asked the young women to decide which violation of a right affected them the most. They took about ten minutes to read through their cards. I asked: 'Who would like to speak first?' When Joan announced that it was the UNCRC's Article 23: 'Disabled children and the right to special care, education and training that will help them to enjoy a full and decent life with the greatest degree of self-reliance and social integration possible', the whole room erupted:

I can't believe it ... I chose that one too.

Me too!

Me too!

Here were young women with a *disability* who were shocked to learn that each of them had chosen Article 23 as their most violated right. They were connected by their shared experience of societal ableism, and they did not know it – until now. Somehow, even after several weeks of group discussion, they believed they were isolated in their experience of living life as a struggle. This day they made the connection. They were not isolated, not abnormal in their experience, and they realized that their lived-experiences of marginalization connected them. This moment of emancipation – of emancipatory nursing – was palpable.

There is value in story-telling for in sharing our true lived-experiences, consciousness-raising begins (Banks-Wallace 1998). To realize that their experiences were not their fault but stemmed from prejudice and ignorance was emancipatory for these young women whose lives had been defined by their Spina Bifida. It was their *light-bulb moment*, and bearing witness to that as a nurse exemplifies the privilege of being a nurse. Following the initial realization of their common-

ality, there was a feeling of peace in the otherwise sterile room which was littered with pamphlets and posters about how to *prevent* Spina Bifida – prevent the very people whose spirit had just changed me, and each of us, forever.

At this moment Carolyn reached for a necklace she was wearing and showed us the unicorn at the end of it:

After my brother carried me home after being beaten he bought me a unicorn on a necklace and said: 'Whenever you're down, you will have everything you will need.' A unicorn is known to bring strength and has magical and healing properties.

It is immoral that anyone should feel the need to rely on a unicorn to magically heal the hurts and scars caused by societal marginalization and hierarchy. Clearly, the brief narratives included in this manuscript demonstrate that to be marginalized and stripped of dignity, power and respect is an infringement of the rights afforded to children: rights outlined in the United Nations Convention on the Rights of the Child. As a nurse in a country which has signed and ratified this treaty, I believe it to be my ethical responsibility to protect and advocate for children's rights.

The day's discussion illustrated to all of us who participated that the very basic right to *know* that children had rights (Article 12 of the UNCRC) had been breached, and that the specific right (Article 23 of the UNCRC) pertaining to children with disabilities was not protected for any of the girls living with Spina Bifida. Time and again they described instances where they tried to have a say about decisions that affected them; asked for respect and dignity; requested assistance with schooling and asked to be included in activities with able-bodied peers. Time and time again, their requests went unmet. Their right to have peers, health care professionals, professionals or schools consider their best interests and keep them free

from harm as outlined in the UNCRC had not been protected. A breach of their right to quality education and the highest quality of healthcare was evident in their narratives of maltreatment. And lastly, their rights to be free from discrimination, abuse, and neglect were the rights most often denied.

Olkin (1997: 32–33), a self-defined disabled therapist, goes farther than the UN Convention by suggesting that children with disabilities should also have the following rights:

- (i) to be told the truth and to ‘own the story’ of their disability;
- (ii) to be in control of their own bodies;
- (iii) to not be treated as a specimen and not to be made to feel that people like them should be prevented;
- (iv) to have a positive identity which includes and incorporates the disability;
- (v) to be allowed to experience a full range of emotions;
- (vi) to have expectations of sexuality, romantic love, and parenthood;
- (vii) to live in a barrier-free and accommodating physical and social environment;
- (viii) to see positive role models of adults and children with disabilities; and
- (ix) to be a child.

The young women I met with described specific violations of exactly these rights. Melissa told us of the constant expectation that she remain patient when she was told that there was no funding, or that she should be on time for class, despite her difficulty in ambulation. Carolyn told us of the expectation that all disabled people should be nice, never get angry and try to understand that those without disabilities ‘just don’t get it.’ The experience of being dismissed, viewed as stupid, excluded, seen as their disability, pathologized and pitied is not only a denial of their rights but directly impinged upon their health and quality of life.

BEING VIEWED AS ‘OTHER’

If we return to the earlier definition of ableism, it is evident that the lived-experience of ableism is one of social marginalization and denied rights. To be marginalized, to be viewed as *other*, is a social category of exclusion and devaluation that, Gerrard and Javed (1998: 104) argue, has significant impact on mental health. When one group is categorized as *other*, a dangerous dichotomy is established between the standard or normal group and the other. This dichotomy is the beginning of oppression.

Oppression serves to define groups like women, lesbians, the disabled, racialized people, and so on as other, different and therefore deficient when measured against a yardstick that assumes that white, heterosexual, able-bodied, English speaking, middle-class men are the social norm:

The root of the word ‘oppression’ is the element ‘press.’ Presses are used to mold things ... something pressed is something caught between or among forces and barriers which are so related to each other that jointly they restrain, restrict or prevent the thing’s motion or mobility. Mold. Immobilize. Reduce.

(Frye 1983: 2)

Frye’s (1983) definition of oppression, when taken metaphorically, is powerful. The lived-experience of the young women with Spina Bifida illuminates the metaphor in continual experiences of denied rights, abuse, pathologization, and disempowerment. To experience life as a constant struggle, all the while knowing that you are viewed as an inconvenience to the majority, has a long-lasting impact on health. Gerrard and Javed (1998: 114) argue that being defined as *other* includes being viewed as deficient in certain valued attributes including being able-bodied, and explain that ‘the psychological impact of otherness includes an erosion of self-esteem, limited achievement, isolation, difficulties in relationships and an [eventual] internalization of one’s otherness.’ The ‘catch-22’

associated with otherness is critical for nurses to recognize:

If [individuals] live their lives as the 'other', they are marginalized and labeled as dependent, deficient and masochistic. If they resist living such lives, they are seen as invaders. Both of these paths have pain and suffering. Living and 'otherness' engenders feelings of alienation, loss and isolation. The silence imposed engenders a deep sense of isolation because [those deemed 'other'] cannot share their suffering or pain with each other or articulate them in society.

(Gerrard & Javed 1998: 115)

The room erupted when the young women described in this convening came to the realization that their experiences of marginalization were rooted in ableism. Their realization that they did not have to accept being relegated to the margins of society was transformational. In that moment when the isolation and alienation of so many years began to unravel, and as the girls eyes lit up I realized the necessity for nurses to be social advocates. Insight building was one step, but there were many more ahead of me.

MARGINALIZATION, ABLEISM AND HEALTH

Oppression serves to marginalize those considered to be 'other', such as women, lesbians, racialized women, and to dismiss them as insignificant, unimportant, invisible, different, of less value and not normal (Gerrard & Javed 1998). The oppression experienced by the participants came in many forms at each stage of their experience with ableism. This included being ignored, dismissed, silenced, rejected, controlled, disbelieved, constantly being compared to others, devalued, victimized, scrutinized, judged, made to feel not good enough and not important, were not listened to or taken seriously, and had little or no agency in their lives or in their interpersonal relationships. In

other words, their rights were infringed upon, if not denied. The majority of times when the young women told stories of anger, it was about their needs being discounted, feeling unappreciated, treated as unimportant and rarely if ever listened to and having no agency. Societal marginalization is another form of oppression, and many of the participant's were marginalized either because of their gender, race, ability, appearance, sexual orientation, or because they were pregnant or young moms. This oppression leads to a social state of otherness. Gerrard and Javed (1998: 114) believe there to be many negative psychological impacts associated with being othered including impediments in self-development, self-esteem, achievement, isolation and loss of self in:

Women internalize otherness by defining themselves as the other. Women live their otherness by giving up many needs, aspirations, and their sense of self – in fact their self-reality. They learn to have selective expression, for example, certain emotions such as anger are ignored.

(Gerrard & Javed 1998: 114)

Gerrard and Javed (1998: 115) go on to say that being viewed as other creates isolation, and that this isolation increases for women such as 'racialized women, lesbians, disabled women, whose otherness exists in more than one way'. Miller (1985) argues that women's assigned subordinate position generates anger. She further claims that repeated instances of repressed anger produces frustration and inaction which in turn leads to feelings of weakness and a lack of self esteem. In this way she is suggesting that oppression creates anger, strips people of their ability to act on their circumstances and an erosion in their self-esteem (see Figure 1).

The narratives clearly demonstrate how societal ableism denied the girls of their rights to self-determination, dignity, and inclusion. In being seen only as their disability, the quality of

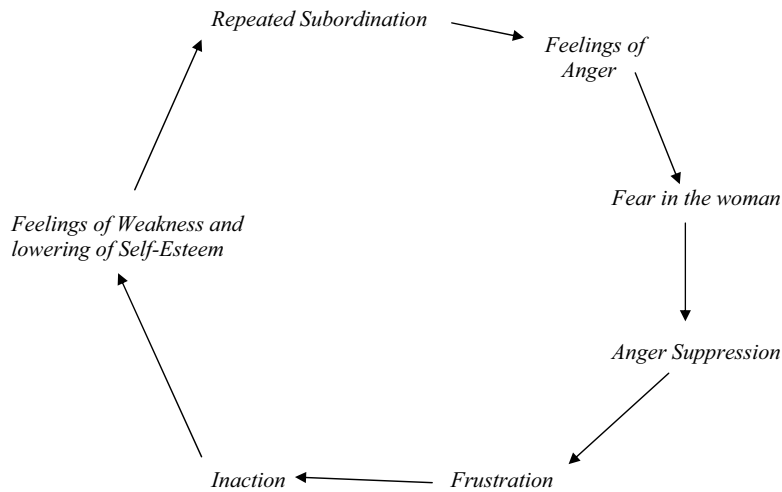


FIGURE 1: REPEATED SUBORDINATION AND FEELINGS OF ANGER (MILLER 1985)

life for girls with Spina Bifida is impeded. To be viewed as a subordinate, as a not-as-good-as-others is one thing. To expect persons living with a disability to not only accept this position in life but to believe it is true is horrifying. Until we met, and came together in dialogue, *none* of the girls had ever named their anger nor linked it to societal and systemic bias rooted in ableist notions of what *normal* is. It is clear from the narratives of these young women social intolerance for disabilities has an impact on health, and the marginalization of the *disabled*, I would argue, is an act of violence:

Until we are all free, no one is free.

(Audre Lorde 1984)

CONFRONTING ABLEISM: A CALL TO ACTION FOR CONTEMPORARY PEDIATRIC NURSES

Personal accomplishment is almost impossible in the human categories that are maintained collectively in an inferior situation.

(Simone de Beauvoir 1949)

Internationally, nursing has a rich history in promoting the health of communities – especially communities who experience societal marginalization. We have long attended to the social

determinants of health and have an ethical imperative to address issues of dignity, justice, equity and sustainable health and well-being. It makes sense, then, that nurses name and confront systemic marginalization rooted in bias and discrimination especially because of its impact on health and quality-of-life. The ethos of nursing, the very fundamental principles which guide and define our way of being, is rooted in our responsibility to advocate for social justice and the health and dignity of all individuals. This responsibility is captured in various nursing codes of ethics including the CNA (CNA 2002:6) *Code of Ethics* for registered nurses. This code, as just one example, identifies eight primary values that, in combination, frame ethical nursing practice. These primary values include: ‘safe, competent and ethical care, health and well-being, choice, dignity, confidentiality, justice, accountability and quality practice environments.’

The narratives included in this essay remain haunting to me still. While I know that I made a difference to these girls, I worry about the lack of an organized thrust in nursing to be social advocates. We must garner the strength it takes to name and confront problematic hateful notions about groups of people. Ableism is root-

ed in ignorance and hierarchy, and the cumulative impact impinges upon the health of those deemed disabled. This is unacceptable. But, we already have the tools to change it. Nursing already has an ethical responsibility to 'advocate for the health and well-being, dignity and justice afforded to individuals and communities' (CNA 2002:6). And because of our ethical responsibility and the privilege afforded to us to bear witness to people's lives, it behooves us to both name and confront systemic discrimination. Institutions that teach future nurses about our discipline must begin to explicitly highlight our responsibility to work for social justice. Nursing is not a profession that is meant to serve the status quo. Rather, rooted in the right to health for all, nurses in fact *must* advocate for the dignity and self-determination of all persons. If not for these five girls, then for whom?

To do anything less would, in my view, make us complicit.

CONCLUSION: RACHEL CARSON AND MELISSA

In many parts of the world, a troubling hierarchy exists which oppresses and devalues people and things deemed of lesser intrinsic value. The ideologies of power and greed that sanction the oppression and exploitation of animate and inanimate nature are the same ideologies that oppress those deemed 'other' in our patriarchal culture. Ableism is just one ideology that suggests that to be anything other than able-bodied is abnormal, ill, and of low social value.

Over 40 years ago, Rachel Carson warned us of the inevitability of a *silent spring* if patriarchal and capitalist societies continued to abuse the natural environment. This silent spring, she said, would be void of the voices of birds. Carson's adept critique of mankind's desire to control and economically exploit nature, while written over forty years ago, still rings true today. Her silent spring was a metaphor for the silencing of nature. To view humans as more valuable than nature, and to view able-bodied humans as

more valuable than disabled humans is a recipe for both social and planetary disaster. Hierarchy serves one purpose: to marginalize the many for the benefit of the few.

There was a reason I was reading *Silent Spring*, while in transit to my meeting with these girls who were living with the societal impact of ableism. Through the narratives of five girls living with Spina Bifida, it is evident that they, too, are silenced. Melissa's left arm, Carolyn's unicorn and Carson's metaphor of a silent spring are all connected – connected in their silencing. Melissa's left arm was silenced because of its deformity, and so too was Melissa. Carolyn's unicorn had to be her voice and strength, for she was not afforded any. Instead she had to rub a silver unicorn that dangled from a necklace and hope that today she'd be listened to, heard, and not beaten up because of her disability.

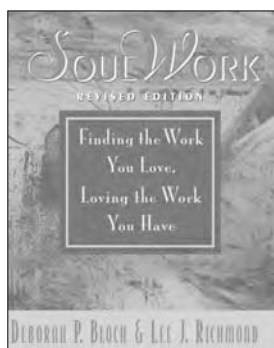
There really are no coincidences, just connections to be made that lie in wait on our horizons of awareness. Carson's silent spring is hauntingly evident in Melissa's mom having to be her societally silenced voice: her left arm.

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