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“I’m not a saint”: Burden Assessment as an Unrecognized Factor in Prenatal Decision Making

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Prenatal testing is widely utilized, yet few studies have explored decision-making processes about diagnosis from the pregnant woman’s standpoint. This qualitative, exploratory study reveals a factor not accounted for in prior research geared toward associations between demographic categories and decisions. The 30 women in this study demonstrated a three-part decisional trajectory that included an effort to collect information about the challenges a potential child with their particular diagnosis might experience. They then assessed their social context, familial supports, and resilience as a couple. A final yet crucial step was an assessment of the woman’s own capacity to provide this level of care within her unique context. Few genetics teams have a member with biopsychosocial expertise and time who can help the woman/couple reflect on the situated context of the decision and its impact. Better care strategies to support women and couples through this experience are warranted.

Keywords: *abortion; decision making; disability; genetics; medicine, reproductive; perinatal health; psychosocial issues*

Advances in prenatal testing have occurred quickly, enabling women and couples to make choices about whether to continue an affected pregnancy and thereby forcing them to grapple with decision making that has ethical, economic, and emotional consequences (Geerincq-Vercammen & Kanhai, 2003; Goodley & Tregaskis, 2006; McCoyd, 2003, 2007; Rapp, 1999; Smith & Gallo, 2007). Decisions about whether to continue a pregnancy affected by a fetal anomaly most frequently occur under conditions of uncertainty about the specific likelihood of fetal anomaly (because the level of risk is given as a statistical function), and uncertainty about level of functional impairment of the fetus if brought to birth (Lawson, 2001; Rapp, 1999; Schectman, Gray, Baty, & Rothman, 2002; Vakin, Ben-Ami, Reish, Herman, & Maymon, 2006). Furthermore, these decisions are constrained by political and medical structures that limit the time frames for decision making. For instance,

most states in the United States will not allow women to terminate an affected pregnancy after about 21 weeks of gestation (Alan Guttmacher Institute, 2006). Social factors are further intensified by discrepant norms about abortion, disability, and prenatal bonding (McCoyd, 2007, in press).

Prenatal diagnostic technology advances allow fetal diagnosis of many disabilities including genetic anomalies, aneuploidy, and many structural defects of the heart and central nervous system (Benn, Kaminsky, Ying, Borgida, & Egan, 2002; Khoshnood et al., 2005; March of Dimes, 2006; Vintzileos et al., 1997). This is complicated by the uncertainty of prognosis; structural, chromosomal, and some genetic conditions can be diagnosed, but the degree of severity is not diagnosable prenatally (e.g., Trisomy 21 entails cognitive deficit, potential for gastrointestinal complications, and proclivity to later leukemia; Benn et al., 2002). When a diagnosis is made, parents must decide whether to continue an affected pregnancy or not. Yet little is known about the processes women and couples go through as they make these decisions.

Ethical dilemmas arise at the intersection between disability diagnosis and decision making about pregnancy termination. Ambivalence about the justification

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of ending a pregnancy intersects with ambivalence about the nature and quality of life a person with a disability lives in the United States (Bosk, 1992/1995; Bryant, Hewison, & Green, 2005; Johnson, 2003; Lassetter, Mandeleco, & Roper, 2007; Lawson, 2001; McCoyd, 2003; Sawyer et al., 2006; Shapiro, 1994; Wendell, 1996; Zitzelsberger, 2005) and the demands for care that continuing a pregnancy can entail (Green, 2007; Morse, Wilson, & Penrod, 2000; Rempel & Harrison, 2007). Impairment and disability are differentiated by Goodley and Tregaskis (2006) and McDermott and Varenne (1995) to emphasize the organic nature of impairment in contrast to the social nature of disability. When cultural norms and societal infrastructures evolve that privilege people born with typical cognitive and physiological characteristics, people born with characteristics that differ from these are routinely disadvantaged and disabled (McDermott & Varenne, 1995). Parents of children who are born with impairments require time to deconstruct and reconstruct what they perceive as "normalcy" (Goodley & Tregaskis, 2006), time that is not available when prenatal decision making occurs under tight time constraints.

The complexity of this decision is increased by the uncertainties connected with diagnosis and prognosis. Indeed, when the diagnosed anomaly is known to be incompatible with life (providing some certainty), research shows women are much more likely to terminate (Pryde, Drugan, & Johnson, 1993; Schectman et al., 2002). Decision-making theorists have focused on the way uncertainty and regret affect decision making (Bell, 1982, 1985; Janis & Mann, 1977; Mellers, Schwartz, Ho, & Ritov, 1997), generally agreeing that beliefs about the anticipated emotional responses to the impending decision influence the decisional outcome. Ambivalence and uncertainty make decision making practically, ethically, and politically challenging.

This article reports one aspect of a qualitative exploratory study of 30 women who made the decision to terminate a desired pregnancy after the discovery of a fetal anomaly (TFA). The title, "I'm not a saint," derives from an *in vivo* code, originally spoken by a clinical client but echoed in most of the research respondents' explanations of the factors they weighed in making a decision. This self-assessment and unique analysis of familial and societal constraints and supports is very specific to each woman's situated context, a process not accounted for in the decision-making literature.

Methods

The full study upon which this article is based explored decision making, the medical experience, social supports, and the emotional trajectory after TFA. Here, I explicate the decision-making process. The theory I develop about processes women experience and elements they identify as influencing their decisions is derived from decision-making themes and analysis of the women's narratives. One aim of this study was to understand the factors women weigh in making their decisions in a way that captures the depth, complexity, and nuance of the experience (Needleman & Needleman, 1996; Padgett, 1998; Patton, 2002; Ritchie & Lewis, 2003), while also developing theory and/or hypotheses about processes and experiences (Drisco, 2006; Glaser & Strauss, 1967). Quantitative research, as noted above, has focused on demographic variables of mothers and parents and the ways these correspond to decisions or, when researching emotional states, on anxiety and grief as measured by scales during and following decision making.

This qualitative research design elicited the narratives of women about their experience of diagnosis, decision making, termination, and emotional responses after the TFA. Theoretically driven sampling occurred to the point of saturation (Miles & Huberman, 1994; Padgett, 1998) to generate information related to each of the sensitizing concepts (Beeman, 1995) of intrapsychic issues and interactional challenges in prenatal decision making and bereavement. Data were gathered from care providers, including 10 social workers (focus group) and three physicians (intensive interviews) who worked with this population, as a way of contextualizing the issue, triangulating data, and enhancing rigor and credibility. As with most qualitative research, earlier interview responses (and access issues) led to modification of sampling inclusion criteria (expanded to cover later gestational ages and longer and shorter times from the time of termination) and interview method (including face-to-face, telephone, and e-mail; see McCoyd & Kerson, 2006).

Inclusion Criteria and Ethics

The women in this study all had desired pregnancies that would not have been terminated had an anomaly not been diagnosed. A full ethics review was conducted by the Bryn Mawr College Institutional Review Board (IRB) because of pregnant women and

fetuses being vulnerable, protected groups (and despite the fact that at the time of the interviews, the women were no longer pregnant). After IRB approval, 30 women responded to recruitment letters disseminated by physician offices and via a peer-support Web site (the facilitator of the Web site's list-serve also provided formal approval). The women were all White (28) or Asian (2), and ranged in age from 21 to 45, with the majority of the study group in the 31- to 35-year-old bracket. One quarter were high school graduates, half had bachelor's degrees, several had master's degrees, and five had doctorates. Nearly all respondents self-identified spiritually in some way; the group included 10 Protestants, 8 Roman Catholics, and 5 Jews, as well as individual members of other faiths, and nearly all indicated that they observed practices of their preferred religion on a regular basis. Because of the use of e-mail interviewing, the women were geographically diverse, with half coming from the Northeastern United States (PA, NJ, and NY) and others from states as far as south as Florida and as far west as California, with several midwestern states represented as well.

Data Collection and Analysis

Intensive interviews (ranging from 2 to 4 hours for face-to-face or telephone interviews; usually 10 to 15 interactions by e-mail) were completed and transcribed verbatim after a complete informed consent process including verbal explanations, question-answering, and finally signing of consent forms. The interviews cohered around the respondent's phenomenological narrative of her experience. I asked each respondent to tell the story of (a) how she discovered the diagnosis, (b) how she made her decision, and (c) how her bereavement process progressed after the decision and through the time of the interview. During the interviews, particular attention was focused on the factors women said influenced their decisions. Data were then analyzed using techniques of grounded theory (Glaser & Strauss, 1967) using a matrix (Miles & Huberman, 1994) to assure that varied aspects of the intrapsychic and interactional challenges were examined. The matrix included (a) the individual responses and decisional strategies of the respondent, (b) her reports of her partner's and children's responses, (c) her reports of the extended family's responses, (d) her experience of the medical system (particularly genetic counselors at the time of diagnosis and physicians and nurses at the time of termination), and (e) the perceived impact of societal

forces. Transcripts were open coded for emergent themes while also analytically coded by level of interaction (e.g., interactions with family; interactions with medical personnel). Data analysis was completed in the traditional constant comparative analytical manner (Glaser & Strauss, 1967). All transcripts were copied in triplicate to aid analysis by boxes of the matrix, as well as by emergent themes (Miles & Huberman, 1994) regarding decision making and bereavement, interactions on varied levels of ecosystem (Bronfenbrenner, 1979), and the emotional impact of the experience. Within the box of decision making, codes of interactional factors and intrapsychic challenges were explored and subcoded into the themes found below. Peer debriefing (with a fellow doctoral student) and member checking (with four respondents) were used to enhance trustworthiness.

Reflexive Analysis

As a feminist, constructivist clinician who has worked for over 20 years in perinatal health care, I was aware that my perspectives and experiences would impact my analysis of the data (Charmaz, 2000; Gouldner, 1970/1999; Haraway, 1988) as surely as they helped in framing my research questions. I reflected on these possible biases with a doctoral colleague who had little expertise in perinatal health care (other than as a mother) and a doctoral committee member who did not have children (as someone able to notice assumptions of childbearing mothers). I am often viewed as inconsistent in value set because of the fact that I am strongly pro-choice but I also strongly support prenatal bonding and mourning for lost pregnancies. Both of these positions are consistent with my primary value that only an individual herself can fully understand the factors impacting her life and choices and so I support, fully, whatever informed, deliberative choice an individual makes (Thachuk, 2007). Furthermore, I, like many, am troubled about the possibility that prenatal diagnosis and termination might act in an eugenic fashion and I advocate for the rights of people who are living with impairments and disabilities; yet here too, I listen to the women in this study group and my clients and hear the ways that their decisions are deliberated and I feel the need to support them in their choices. The professional value of self-determination (National Association of Social Workers, 2000) combined with a strong valuing of relational autonomy (Christman, 2004; Mackenzie & Stoljar, 2000) guides this analysis.

Results

Two thirds of the women in this study reported that after they received a diagnosis of a fetal anomaly they hoped (some said they “prayed”) that they would miscarry naturally. They desired a reprieve from the decision making and the responsibility that was thrust upon them after the diagnosis of an anomaly. The women in this study primarily had fetal diagnoses which were not incompatible with life (25/30). When decision making was necessary, the trajectory included collecting information about the impact of the diagnosis on the potential child, determining whether the condition was incompatible with life (e.g., Trisomy 13, anencephaly), assessing the potential burden of the condition on the potential child, and further assessing the impact on the mother herself and her family. Finally the women envisioned how such a life would look and considered their capacity for managing either of the potential outcomes—a loss through TFA (termination for anomaly) or the delivery of a child with a disability. As diagnosis became clearer, the respondents reported that they started to integrate the fact that the diagnosis itself had ensured that they would experience a loss; they would either lose the child altogether through termination of the pregnancy, or they would lose the healthy child they originally envisioned birthing.

“The world doesn’t know how to accept people with the kinds of disabilities she would have”: Decision Making and Disability in Societal Context

Social ostracism. Respondents reported being swayed heavily by the thought of subjecting their children to the suffering (because of pain for some and stigma for others) they believed people with disabilities experience in U.S. culture. Helen¹ did not initially think she would have a TFA. Her female fetus was diagnosed with spina bifida:

Over the next week or so, we talked to as many people as possible. We met with a genetics counselor, who gave us facts that sounded manageable. Then we met with a physician who leads the SB [spina bifida] clinic. . . . He shared with us his real-life experience with spina bifida and its effect on the people who have it and on their parents. I cried all the way home from that visit. My husband kept referring to him as “Dr. Death.” But the truth was that he was telling us exactly what we didn’t want to

hear—that nothing we could do would create a truly high quality of life for our baby girl. That her life would be painful, physically and emotionally, that she would have multiple surgeries, that the world doesn’t know how to accept people with the kinds of disabilities she would have. Despite that, I was adamant that I would not terminate . . . but it had planted a seed of doubt.

Notably, Helen reflects something that the vast majority of respondents reported: their genetic counselors and their obstetricians or perinatologists were nondirective in terms of their decisions. Some steered the women toward resources where they could explore what it might be like to parent a child with the diagnosed disability, either by visiting another physician or service provider who works with people with that diagnosis or by communicating with a parent of a child affected by that diagnosis. A large minority (11) of the women in this study actively wrestled with the ethical and political implications of their decision making. Ricki worked for a disability rights and advocacy self-help organization before receiving the news that her fetus had spina bifida. She feared telling one of her close friends with whom she had worked:

I have a good friend who uses a wheelchair, has cerebral palsy, has a mild form of Chiari malformation herself (though I didn’t know it at the time), and is pretty severely disabled herself. And she is one of the sweetest most wonderful friends I have, we worked together at [disability rights organization]. And she and her husband are trying to adopt a child and were considering adopting a child with disabilities. So I had great trepidation telling her. I felt like this was—I just hoped so much that she wouldn’t see our decision as a denial of who she was. What if she chose to see this as, “We don’t want a disabled child at all because we don’t think people with disabilities have a life that is worth preserving, or a life that’s worth honoring?” . . . But I really, really, really cared what she thought. And she also turned out to be totally wonderful about it. She and her husband both were like, “We know that you two can handle adversity, because of Robert’s mother being in a coma for 4 years and you taking care of her, so we know that you can do hard things and it’s not that you are squeamish and can’t do it, so you must have had good reasons and so we support you.” And that was the most wonderful thing of all! It was one of the most meaningful of all the friends we had to tell. And she was really sad. I mean, she cried. It was obvious that it hit her in a very hard way, and yet she didn’t judge us. It was incredible—it humbles me.

Ricki reported that during her bereavement she continually reexamined the ethical and political aspects of her decision in ways that initially complicated her grief. She eventually felt reassured by the support of her friends who were living with disabilities, and this ultimately assisted her in moving through her grief.

Katherine, too, struggled as she considered the implications of her decision about her fetus with Down syndrome. She is a teacher who worked in special education at one point in her career:

I knew going in what it would mean to have a child with DS [Down syndrome]. I remember all too well how cute and sweet and loving the little ones could be. I also remembered how hard to manage the teen boys were. Not that all teen boys cannot be hard, but with DS kids it's a different story. I remember in my teaching that we had to make sure they did not get too bored. If they did, they would start masturbating or trying to touch other students. It was hard as a teacher. As a mother I could not imagine it. I have thought about my decision many thousands of times. I think if I had been having a girl I might, just might have considered having her anyway. If I had other children besides my daughter I probably would have, knowing that in later life they might share the burden. But having a boy, having only one other child, and knowing what I knew about when they are no longer so "cute," well I chose not to have Leif.

Respondents reported spending time exploring the fetus's condition and becoming informed about the physical maladies, isolation, and social stigma people with disability are likely to experience in U.S. culture. They chose to avoid such suffering on the part of the fetus, as well as for their other children and themselves. They seemed to intuit that the stigma of disability would affect them and their families, something affirmed by many parents of children with disabilities (Ladd-Taylor & Umansky, 1998). They are exquisitely aware of the fact that they will have different perceptions of their child with a disability than others in their cultural context likely would. Sarah describes how she sees the beautiful newborn (diagnosed with craniostenosis and delivered by induced premature delivery) she knows that society would not see:

So, on [date] I delivered my son Jared's body. I remember thinking right away that I had to see him. I had to see my son. Even though I strongly believed

it was just my son's body, I still needed to see. They brought him to us all swaddled in a yellow blanket. He was beautiful, he had his daddy's dark hair and I think his daddy's chin. But, his anomalies were easy to see. It's funny how even to this day when I look at his pictures, my heart tells me his anomalies were not that bad. But logically I know, they were. I think the reason I only see a beautiful little boy is that he is—to me. He is my son and I am his mother. I and my dear husband can see the sweetness in his little face that the rest of the world would not have.

Knowing that society would not be as accepting and loving of a child with a disability as they would be was something that several women identified as playing a role in their decision. They indicated that they would accept such a child, but that they could not accept the fact that society would not accept their child. This aspect of society was not something they believed they could change; it was taken as a "given," framing their decision making. Despite disability rights advocacy and advances in creating more inclusive social environments, these mothers were sensitive to the stigma, rejection, obstacles, and disabling culture (Goodley & Tregaskis, 2006; McDermott & Varenne, 1995) that they felt unable to change, or to tolerate affecting their child.

Financial and resource limitations. Respondents also reported awareness of and concerns about the realities of meager financial and social support, leading to high cost and care burdens. The lack of good social support in the United States for raising children with disabilities is an aspect over which parents have no control (Lukemeyer, Meyers, & Smeeding, 2000; Parish & Cloud, 2006). Even some who might have been inclined to continue a pregnancy chose to terminate because of the reality of financial, social, and emotional burdens that would be theirs alone to manage. They asserted that the financial and other stresses would have detrimental impacts on their marriages and ability to raise other children. Urika's fetus was diagnosed with agenesis of the corpus collosum along with other structural brain abnormalities. She is quite aware of the paucity of concrete help:

I should backtrack here. It wasn't so much about the quality of life she could have—it was also about our immediate situation. Neither of us have living parents or immediate family that we're close to. The relatives that we do have are nice on a superficial level, but not real helpful and we're not very close.

And we're basically working schmoes—we have no savings. And I do know someone whose baby was diagnosed with cerebral palsy and seizures at 4 months old and they told the parents he probably wouldn't live past his 12th birthday. He died at 25 and they went bankrupt twice. These are working people. And I said, "We just can't go through what they went through. We just don't have the resources." It's all about resources that we didn't have. That poor woman who had that child 28 years ago didn't have any choices, but I do and I think I have to put some foresight into this.

The lack of societal support in the United States for parents whose children have disabilities made the respondents wary of taking on the financial, energy, time, and emotional commitment that it takes to raise children with disabilities. While Urika was one of only two who directly expressed concerns about financial resources, nearly three quarters of the study group focused on how caring for a child with a disability could keep them from meeting responsibilities to their marriage and other children. The mothers believed that they could not independently change the way that their child would fit into society or the economic burden, and they factored this into the decision to terminate the pregnancy.

"I did do this thing for myself and my family": Impact on the Family

Aside from the societal factors discussed above, respondents also considered the impact of having a child with a disability on their marriages and on their living children. Felicia stated,

We don't want [our sons] to feel like they've got to be her caretakers for the rest of her life. We talked about the baseball season and I was saying I don't want to miss Tucker's games because he doesn't want me there with a little sister who will embarrass him, or I don't want them to feel like they can't bring their friends over because of her, you know . . . and I knew that it wasn't something to be mad at my kids about either—that it was just the way it was.

More than half of the women reported being concerned about the impact of a child with a disability on their other children—even though some had no living children yet. Katherine struggled as she acknowledged this to herself:

I did do this thing for myself and my family. Not for Leif [the fetus]. I did not do it for him at all. Maybe

he would have suffered. Maybe not. Maybe I did not want to imagine an isolated, lonely, depressed, retarded adult man. So maybe I did spare him that end. But life had no guarantees for any of us. We all face the possibilities of leading a sick, unhappy life. So I cannot insist I did it for him. I did it for me. I did it for my marriage. I did it for my other child. I did it for my home and job and way of life.

Brenna and her husband also struggled with the ramifications of a diagnosed fetal anomaly, in terms of both societal and family roles and available resources:

But when we discussed it, we thought, nonhealthy babies are very, very expensive; they put a lot of strain on a marriage; they impact any children you might have in the future; they affect every aspect of your life. And Dan left it to me because he said, "I'll be going off to work everyday and you'll have to stay home with this baby, so you have to make the decision." At the time, I was planning on going back to work and what would we do for day care?

Most women asserted a belief that marriages become stressed and prone to divorce when children with disabilities are born. None suggested that this was the sole reason for their decision, yet many alluded to this and its role in their decision. Again, their assessment of the strength of their marriage, the potential impact on their other children as caregivers, and the economic impact on the family were all factors they weighed in the context of their decision making. Ultimately, the factors above were filtered through an assessment of their own capacities.

"How could I have a child like this being the way that I am?": Decision Making and Self-Assessment

As women and couples gathered information about the anomaly, they became more bonded with their fetus, but also more informed about the challenges and suffering the potential child would be likely to experience if born. Once this picture of the potential child's future became clear, they began to think about how this new understanding fit (or not) with the functioning of their family and marriage within the societal context of the United States. These understandings seemed to percolate into a vision of "how it might be," and led to a time of reflection on their individual capacities. This was also a time of rude awakening, a time of coming face-to-face with one's own

limitations. Slightly less than half of the women reported that they initially felt the desire to act in idealized ways; they wanted to lovingly accept the potential burdens that the birth and parenting of a disabled child would create. Decisions to terminate were made after the (envisioned) reality of the changes that birth would entail in the woman's and her family's life emerged. At times, as discussed above, the women focused more on the potential impact of a child with disabilities on other children and the marriage. Other times, though, the woman reported facing herself and realizing that she did not feel capable of raising a child with the diagnosed anomaly.

Brenna, when newly diagnosed with a fetus with triploidy, posted a question on an Internet chat board dedicated to the discussion of trisomy genetic conditions. She had a number of women write to her of their experience delivering their baby and having a day or two with their newborn before she or he died. Brenna commented,

And it was insane to me—but they really treasured their time with their children, even if it was only 2 days. “I went to term and delivered a stillbirth”—they all told me their stories and while I thought it was amazing that they were the kind of people who could carry a baby another 20 weeks knowing that it was going to die, it was incredible to me [said with sad admiration]. But I knew I wasn't one of those people. I knew I needed to move on with my life and have another.

With the recognition that some people are able to parent children with these demands, and the awareness that she is not able or willing, nearly all of the women in this study reported experiencing a high degree of guilt. This guilt was not as much about the decision to TFA as it was for not being the type of person who could withstand the rigors of parenting a child with those challenges in this society. This was the sentiment my client espoused when she sadly told me, “I'm not a saint,” with the implication that others who provide this care are saints. Beatrice expressed this:

I have guilt for not being the kind of person who could parent this particular type of special need. There is a lot about this [chromosomal] deletion that looks like a mental illness. I grew up with a sister who is schizoaffective. I have a lot of fear about that . . . that was my biggest fear—being utterly exhausted, sleep deprived, and depressed and having a mentally ill or out-of-control, nonsleeping, bizarrely energetic boy. And lo and behold, those

very characteristics are part of the behavioral phenotype that has been identified for the chromosome deletion: it was terrifying. When I began reading about this deletion, I went from being absolutely sure I would not terminate to shaking with terror. How could I have a child like this being the way that I am? There was just no way! So guilt for being the way that I am: having probably had postpartum depression, needing sleep, needing a certain level of control in my life, not being able to sleep with my kid (doing the “attachment parenting” schtick), giving up nursing at 22 months (unlike my attachment parenting friends who nursed until age 3 or so). Guilt, guilt, guilt. If I were a different kind of person, looser maybe, I could do this, I could have had this child, I could have parented this child. But here I am, with my own tremendous limitations.

Beatrice grapples with her limitations, with her belief that she did not have the capacity to endure in a healthy way if her fetus was born. She, like the others, never expressed guilt about having a TFA; her guilt was for not being “the kind of person,” “a saint” that she believed others could be. Felicia's reminiscences might appear socially unacceptable, but they genuinely reflect an experience she had earlier in her life that then framed her decision making, and her understanding of her capacities, in her pregnancy:

I remember another conversation we had—[with her husband] . . . I told him, “There was a guy I shared an office with on Law Review when I was in law school and he had a baby born with spina bifida—undetected. And also, he [the baby] had a shunt wherever they have to put a shunt on the head. And he [the office mate] came in like two days later and we'd all heard and I said, ‘I'm really sorry, that's horrible,’ and he said, ‘The doctors are telling me it's going to be all right. It doesn't look as if the baby suffered any retardation from what they can tell’ . . . And he said, ‘It's all right, they don't think the baby suffered any retardation and that's the thing I was scared about. Felicia, I know it sounds terrible, but I just can't have a stupid child.’”

So I came down here this night and I said to Daniel, “This has been in my head for 10 years and I never knew why I filed that away like that but . . .” And he [the office mate] had said it very calm[ly], “Felicia, I just can't have a stupid child,” and I thought it was a very odd comment. “I could never have the world taking advantage of my child.” And I was just like, it was one of those slap-in-the-face comments that has always stuck with me. This little voice inside was saying, “You have been prepared for this—a child with retardation is not something you can do.”²

Felicia's colleague's statement that "I could never have the world taking advantage of my child" echoes Sarah's description of how she knows the rest of the world would not accept her son the way she would. Both are predicated on an awareness of society's rejection of people with disabilities. While Sarah still expressed her love, Felicia, like her colleague before her, knew this was "not something [she could] do." She could not allow a child to be born who might be taken advantage of, who would keep her (Felicia) away from her sons' athletic games and who would have care requirements beyond what Felicia believed she could handle. It is important to clarify that women often portrayed this as being "selfish," yet it was predicated on concerns about their marriage, their other children, or their own capacities that would limit providing optimal care—not selfishly, but seemingly trying to protect everyone involved.

Erin struggled with her limitations. Her nephew (and her sister's family) was living with the same chromosomal anomaly with which her fetus was diagnosed (which left her nephew unable to ambulate, feed himself, or participate in conversation). She talked about some of her nephew's caregivers:

But they just had the biggest hearts and the most patience with the people in the home. I just knew I didn't have that . . . when the disabilities are so all-encompassing, it's just very hard to relate. And so I bless the people who are able to work with disabilities, like the people who work with my nephew. I feel bad about that about myself, not that I can't—but that I choose not to. It's an uncomfortable place for me.

The process women describe is predicated on this three-part trajectory—gathering information that reveals the extent of (dis)ability for the child who could be born if the pregnancy is continued, assessing the marriage and family resilience within the societal context, and envisioning how one might manage that while facing one's limitations and determining that one cannot be the saint who carries on in spite of the knowledge attained in the earlier two phases. Although the societal and familial factors had great salience for the women in their decision making, their final assessment of their own capacity to cope with the burdens revealed by these assessments was ultimately the primary factor in their decision.

Discussion

Factors affecting prenatal decision making are myriad. The literature on correlations with social

structural variables such as educational attainment and race is robust; women who are highly educated, have higher incomes, and are White are more likely to make use of prenatal testing and to terminate a pregnancy affected by fetal anomaly, particularly when the anomaly involves cognitive deficits (Deverill & Robson, 2006; Dormandy, Michie, Hooper, & Marteau, 2005; Halliday et al., 2001; Khoshnood et al., 2005; Mansfield, Hopfer, & Marteau, 1999; Schectman et al., 2002). The application of decisional aids (Bekker, Hewison, & Thornton, 2004) appears useful despite the heavy reliance on rational choice and utility theory. Economic decision-making theories incorporate emotional aspects (Bell, 1982, 1985; Mellers et al., 1997), but are limited to investment and financial decisions and hypothesized emotions of regret as a result of a poor economic choice. The literature is quiet, however, about the process of self-assessment in regard to one's capacity for providing care for a child with a disability as part of the decision-making process.

Within this study, women whose fetus was diagnosed with a condition that is incompatible with life viewed their decision to terminate the pregnancy as self-evident because the pregnancy would not ultimately result in a living child. The majority of the group who had diagnoses which would allow life, though affected by various levels of impairment, had much greater difficulty with decision making. The decisional calculus they reported required situated knowledge about one's societal and familial context, social supports, and individual coping capacities, as well as an image of how a potential child might be affected. This exploratory study suggests that this assessment of one's situated context and capacity is an influential and prevalent factor which has not been accurately identified and accounted for in our understanding of prenatal decision making for fetal anomaly.

Women in this study did not make their decisions solely on rational choice calculations, as is usually posited (Bekker et al., 2004; Lovett, 2006). Instead, they identified a primary process in their decision making—an analysis of themselves and their capacity to cope within their specific societal and familial networks. The data from this study point to a theory for what might happen "inside the black box" of decision making, and illuminate areas for further exploration in the decision-making process. Although this study is limited by its small number of respondents (30) and its retrospective design with only women who elected to terminate an affected (though desired)

pregnancy, it is a qualitative study aimed at gathering rich narrative data about the experience and its processes. It is important because it strongly implies that demographic and rational decision-making models for explanatory purposes are missing an important process that women view as primary and very individualized. Instrumentation such as anxiety and depression scales and the use of decisional trees might be utilized in quantitatively studying the decision-making process, but they cannot capture other decisional factors that were identified by this study group.

Pressure from others is often anecdotally assumed to occur and to influence decision making. Notably, none of the women in this study reported pressure from their physicians or genetic counselors to make a decision in one way or another. Those who reported any pressure from others reported that pressure to terminate came from spouses while pressure to continue the pregnancy generally came from mothers-in-law or sisters. Pressures from others (other than spouses) seemed to have little bearing on the women's decisions. Most importantly, the women critically assessed their own capacities and the capabilities of their marriage and family to cope with the challenge of bringing a fetus known to have an anomaly to birth, within a society that stigmatizes, "dis-ables," and refuses to support people with impairments. This process required significant time for reflection.

Because the respondents were all interviewed after decision making had occurred, they might have developed rationales that assisted them in coping with and supporting the decisions they already made. The professional literature is quiet about women who elect to maintain the pregnancy, though popular literature, such as novels (Beck, 1999/2000; Zuckoff, 2002), does provide some exemplars. Recently, Green (2007) asserted that women raising children with disabilities experience benefits such as newfound assertiveness and strength as they cope with raising their children. It is unclear if any of her respondents had prenatal testing or faced choices about whether to continue a pregnancy known to be affected by anomaly. It is provocative, however, to consider a quote from a mother in a study of normalization among children with disabilities who claims, "I would have said, 'I don't know how I would handle it and I wouldn't be the right mom for that.' But you handle everything day-by-day, and what is unnatural for someone else is now very normal in our household" (Morse et al., 2000). Lassetter et al. reported the comments of a mother of a child with

Down syndrome that indicate that this same trepidation preceded later acceptance: "When I first had him . . . I didn't know the joys that came along with it and the happiness of having him. And I wouldn't want him any other way" (2007, p. 463). This indicates that each might adapt to the circumstances, but the nature of prenatal diagnosis creates the opportunity for a decision to be made prior to a birth. Either way, with data gathered after a decision has occurred and been implemented, this study, Green's (2007), Lassetter et al.'s (2007), and Morse et al.'s (2000) are all open to the charge that women are rationalizing their decisions after the fact. Ideally, future research will gather prospective data about what women believe they might do ahead of an actual diagnosis. This will allow analysis of the consistency of what is believed prior to confrontation with a diagnosed fetal anomaly with what happens when there is an actual diagnosis. Further, women who elect to continue a pregnancy affected by an anomaly will provide a rich group with whom to explore how preparation enables coping and resource utilization. Comparison of this group with those who have a diagnosis after birth will also provide useful information about the process that enables families to adjust to having a child with impairment/s.

The intersection of prenatal decision making with disability rights and eugenics is an area of concern as well. Shapiro (1994) discusses the views of Asch, a medical ethicist (who is blind):

But selective abortion on the basis of disability, she says, is wrong. Most women who abort a fetus diagnosed with a disability like Down Syndrome, spina bifida, cystic fibrosis, or muscular dystrophy, she claims, lack knowledge of how the disability rights movement is improving the quality of life for children with these conditions. . . . To abort on the basis of disability, she says, suggests a disabled person's life is not worth living. A woman's right to choice is also violated, she argues, when a society expects her to abort a fetus that may be disabled. (p. 280)

Shapiro and others in the disability rights movement believe that decisions made by mothers to terminate pregnancies with fetal anomalies are not ethical. Yet he acknowledges that resources for people who are disabled in this country are sorely lacking. This judgment of TFA as unethical dismisses the fact that women have no control over the society into which their potential child is born, nor over physical aspects of pain and suffering their offspring could endure.

Wendell (1996) points out that some people with disabilities argue for the right to make their own choices about whether they want to continue the physical suffering that is often times a part of the disability. Nevertheless, she worries that abortion might send the message that people with disabilities have lives that are not worth living. She further describes the feminists-with-disabilities position as

recogniz[ing] that, under present conditions in most societies, individual parents, especially mothers (who do most of the care-giving work), must provide the extra resources, especially time and energy, required for raising children with disabilities. Thus many feminists with disabilities support women's right to choose not to give birth to a baby with a disability. (p. 155)

This indicates that, ethically, mothers and parents must be the decision makers. Just as they make medical decisions for young children, they are the ones to decide in the case of a fetus. Even so, Wendell (1996) notes that "screening of fetuses and selective abortion are likely to begin as voluntary medical procedures but become socially mandatory fairly quickly" (p. 155). Indeed, Fitzpatrick (2001) claims that *laissez-faire* eugenics (where the parent/s make the decision) is hazardous and he believes that a "regulated eugenics" (dictated by debated public policy which he believes could ensure social justice) is the ethical path.

Fitzpatrick's call for public debate underscores the need for public consideration of the social justice implications of TFA. His call for policy mandates, however, has less credibility in light of the findings presented here. His focus, and that of many ethicists, is on the narrow question of what circumstances justify pregnancy termination. This ignores the broad societal context in which such decisions are made. Debates about TFA must include the context, including lack of opportunities for people living with disability, lack of resources for families raising children with disabilities, and lack of emotional supports and respite for families with a member who has a disabling condition. A broadened debate might lead to societal responses to develop policies that support people and families affected by disabilities. This study suggests that such change would enter into women's decisional calculus and thus might change the dynamics of women's decision making. Currently, the difficult decision is made by the woman/couple. The woman's assessment of her own capacities within a complex societal and familial

context indicates the need for individual decision making rather than a formulaic policy response. In light of the data presented here about the unique ways women weigh different factors in the decision, only the individual woman has access to all of the information that affects her assessment of her capacity to parent such a child. Only she has the ability to assign meaning to these in a way that will enable her to make the decision that she, more than any other possible decision maker, will live with.

A major implication of this research concerns our lack of full care provision for women and couples as they navigate prenatal diagnosis and decision making. We have no mechanism in genetic counseling to help women navigate this social context and self-assessment. They seem likely to benefit from assistance with considering the ways their own capacities, family resources, and societal context influence their decision. Physicians and genetic counselors are charged with gathering and interpreting medical and genetic data and have little time to add to helping the woman/couple with self-assessment and reflection. Although psychological and social work supports are occasionally available, they are not available in the majority of prenatal diagnosis clinics (McCoyd, 2003). They are seldom portrayed as a normalized part of the care team. The findings in this study imply that psychological and social work supports (which incorporate discussion of normative social influences as well as psychological ones) might be particularly helpful for optimal navigation of the decision-making process. Furthermore, there are strong implications in the full study that women who have processed these decisions more fully and reflectively, either by having considered them prior to testing or by having more time between diagnosis and decision, seem to fare better during their grief process than women who have had little opportunity to reflect on the decision that they made (McCoyd, 2003).

It is known that prenatal decision making for fetal anomaly includes difficult processing of complex information about risk and diagnosis and also involves assessment of the availability of concrete resources for care. Nevertheless, this study strongly suggests that many women might feel more supported and less overwhelmed through the decision-making process if the socially mediated and deeply personal aspect of self-assessment within her social context is both normalized and validated. Normalization and validation can take several forms. The normalization of the need to reflect on one's social context, available resources, and family

dynamics would allow the women to value time spent doing this rather than focusing solely on the medical information physicians and genetic counselors provide. Women appreciate it when care providers validate the difficulty of decision making and the fact that none of the options leads to the women's original goal of having a healthy child.

What is quite clear is that each woman's decision is situationally grounded within her unique social and familial context and bounded by her perception of the way society would support (or not) her child and family. Policy efforts to limit women's options because of concerns about abortion, eugenics, or disability rights serve only to create further strictures. Policy efforts should broaden options for women by (a) improving resources for people born with disabilities, (b) providing supportive counseling for individualized decision making, (c) assuring bereavement counseling availability for women who elect to terminate, and (d) minimizing the stigma of both disability and abortion. Women are the only ones who can calculate which factors weigh most heavily for them and what that means for their decisions. Furthermore, significant time with an appropriate care team member to allow reflection about these individual and family capacities is necessary and might be as helpful as a formal decision-making tool in supporting women and couples through the decision making process. These are empirical questions yet to be explored.

Notes

1. All names (respondent, husband, children, and fetuses) are pseudonyms.

2. Schechtman et al. (2002) found that when a fetal diagnosis included cognitive impairment, parents were up to 90% more likely to terminate the pregnancy for the same level of life threat than when there was no cognitive impairment predicted.

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