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ORIGINAL PAPER

Fostering Insights: A Strengths-Based Theory of Parental Transformation

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Abstract Parent's awareness that their child's development is not proceeding as they expected can create an unanticipated transition from being a parent to becoming the parent of a child with a developmental diagnosis. While many transition theories contribute to our understanding of how parents' experience change over time, many traditional transition models are not family-centered and do not provide a strengths-based perspective of parents' experiences during this transition. This paper describes the process of theory derivation to develop a strengths-based theory of parental transformation (STPT). We used the theory of well-being of refugee women experiencing cultural transition to gain insights into parents' experiences related to their child's diagnosis. We propose that the STPT addresses a gap in the literature by situating the diagnostic process within a strengths' based framework that aligns with contemporary perspectives regarding disability. The STPT emphasizes understanding parents' experiences and needs in ways that promote personal growth to support the parent and child.

Keywords Developmental diagnosis · Family-centered · Parents · Strengths-based · Transition

Introduction

During the 20th century, theoretical models used to understand disability moved from a focus on pathology, impairments, and limitations to a perspective that aligns with developments in the field of positive psychology. Contemporary models of disability emphasize abilities, strengths, and support based on individuals' and families' needs (Little et al. 1998). Family-centered practice and strengths-based approach have emerged as core principles of best-practice for working with children and families (Epley et al. 2010; Workgroup on Principles and Practices in Natural Environments, OSEP TA Community of Practice: Part C Settings 2008). However, while providers typically claim "we've worked with families for 25 years, and we've always been family-centered" (Dunst 2002, p. 147), family-centered care is more often a slogan than practice (Bailey et al. 2006). Family-centered practice is a philosophical perspective that organizations and providers use to deliver services to children and families (Workgroup on Principles and Practices in Natural Environments 2008) and should be the primary perspective used by diagnostic evaluation teams (Braun et al. 2017; Prelock et al. 2003).

Understanding parents' experiences to provide support to families has emerged as an important priority for early intervention (Tomlinson et al. 2014) because parents' health and wellness affects their children (Bronfenbrenner 1979; Morris and Bronfenbrenner 2007). Improving support for parents of children with developmental disabilities is a global research priority (Tomlinson et al. 2014) and includes the need to better understand parent experiences and information needs while a family waits for diagnostic clarification (Crane et al. 2016). Early childhood and healthcare organizations recognize that improving support for parents and children is best accomplished through family-centered services (Kuo et al. 2012). The core principals of family-centered practice are balanced relationships between families and providers, family choice, individualized services and emphasizing the strengths of families' and

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individual's (Epley et al. 2010; Kuo et al. 2012; Millenson et al. 2013). Family-centered practice stands in contrast to problem-focused practices that emphasize deficits (Trowbridge and Mische-Lawson 2014) or staff-centered practices (Ecenrod and Zwelling 2000). A focus on problems or deficits is standard practice in many traditional models of care (Saleebey 1996); as a result, many traditional transition theories do not align with the core principles of family-centered care because the theories do not recognize the diversity of families, or they reinforce deficit-based perspectives of disability. However, acknowledging the possibility of positive outcomes does not mean that the parents' or child's health conditions are ignored or willed away. Just as a failure in the medical model to identify relevant medical conditions increases health risks, in the strengths model, a failure to recognize a parent's condition increases the likelihood of ineffective supports (Buntinx 2013). Increasingly, providers within medical settings recognize that children with complex chronic health conditions benefit from family-centered and strengths-based care (Ecenrod and Zwelling 2000; Trowbridge and Mische-Lawson 2014).

Research on parents' experiences surrounding their child's developmental diagnosis indicates parents often experience stress and uncertainty and higher levels of depression (Crane et al. 2016; Ho et al. 2014; Mansell and Morris 2004). Uncertainty is uncomfortable and may be associated with stress, anxiety, as well as negative or positive outcomes. Uncertainty influences parents' relationship with their child (Page et al. 2012), confidence (Stewart and Mishel 2000) decision making (Guerriere et al. 2003), mental health (Stewart and Mishel 2000), ability to live in the present moment (Rosenthal et al. 2001), and acceptance of their child for who he or she is (Rosenthal et al. 2001).

While family-centered practice and strengths-based approach are not new, a gap remains between theory and practice. The purpose of this paper is to describe the process of theory derivation to develop Broski and Dunn's strengths-based theory of parental transformation (STPT). First, we describe theory derivation, the method we use to develop the STPT. Second, we provide a brief description of the source theory, the well-being of refugee women experiencing cultural transition ([RWCT]; Baird and Reed 2015) including previous research on the RWCT. Third, we present the derived theory and discuss implications for future research.

Theory Derivation

Theory derivation is a method of theory development used to develop insights where existing theories have limited impact on practice. Theory derivation identifies ideas about the essence of practices and attempts to bridge the gap between research paradigms and practice. This process uses analogies from one field of study to develop insights in another field of study (Walker and Avant 2005). The steps of theory derivation include: (a) evaluate current theory; (b) read widely for insight and analogies; (c) select a source theory for the derivation process; (d) identify source theory content for use in the derived theory; and (e) redefine the source theory (Walker and Avant 2005).

Evaluate Current Theory

Transition is a universal experience that occurs over time, requires adaptation and shapes how people respond to change. Transition theories generally recognize three primary stages: (1) an initial phase that involves separation from a previous way of life; (2) an in between phase known as liminality, a state of being betwixt and between; and (3) a final phase that signifies the beginning of the individual's new social role (Kralik et al. 2006; Meleis 2010; Turner 1969; van Gennep 1960). Transition is a common theme in early childhood literature. From the child's birth to entering elementary school, there are many transitions; children may attend daycare or enter preschool, children may experience siblings being born into the family, and sometimes families move. For families that have children who seem vulnerable, the transition experience also includes a diagnostic process as parents seek knowledge and insights to better understand and support their children.

Individuals structure their expectations about each phase of life and assign meanings to life-events, and to their roles in those events (Becker 1997). Individuals may feel at odds with themselves and with others when life unfolds in ways that do not match the individual's expectations (Becker 1997). Work and leisure activities may change, and disruptions may occur in patterns of personal expression (Kleiber et al. 2002). Parents' awareness that their child's development is not proceeding as they expected often creates an unanticipated transition (Meleis 2010; Messias et al. 1995) from becoming a parent to becoming the parent of a child with a developmental disability. While parents frequently perceive unexpected transitions as negative developments (Messias et al. 1995), all transitions require individuals to reflect on their lives in ways that can be transformative (Chick and Meleis 1986; Kleiber et al. 2002).

Numerous transition theories contribute to our understanding of how families experience change over time. While many general concepts about transition contribute to our understanding of parents' transition, some traditional transition theories are not family-centered. To accurately portray the situation for families waiting for a developmental diagnosis, some family-change theories require updating. For example, Meleis (2015) indicates a change in health or illness, such as cancer, diabetes or autism can trigger a transition (p. 364). While we agree that concerns about the child's developmental progress may serve as a trigger for transition, many developmental diagnoses, including autism, do not represent a change in the child's health. Rather, the diagnosis represents how health care or education systems classify the child's functioning. While it may appear to be a minor incongruity, it is essential to frame developmental diagnoses accurately so that research paradigms and professional recommendations do not inadvertently imply a child with a developmental disability is sick or requires a cure.

Just as services provided throughout the diagnostic process occur along a spectrum of deficit-based or strengths-based practices, the theoretical frameworks researchers use to study parents' experiences reflect paradigms that range from deficit-based to strengths-based. Examples of research paradigms that inadvertently emphasize deficit-based perspectives include closely focusing on parents' interactions with the medical system, such as satisfaction with the diagnostic process, time required to receive a diagnosis and the number of professionals needed to obtain a diagnosis (Crane et al. 2016; Howlin and Moore 1997; Siklos and Kerns 2007). Other medical model perspectives include finding cures for deficits, and perceptions that professionals are best equipped to address developmental disabilities (Brueggemann 2015). Implicit within some research paradigms is the idea that a clear diagnosis of the child is necessary before the parent can move on or reach closure (Mulligan et al. 2012; Timmermans and Buchbinder 2010).

At the other end of the research paradigm spectrum, studies that emphasize family-centered principles provide opportunities to enhance well-being rather than focus on deficits. For example, Steiner (2010) explored the use of strengths-based language to improve parent and child interactions and enhance parent well-being; and Braun et al. (2017) developed a framework to explore whether interdisciplinary clinicians write parent reports from a strengths perspective.

Additional evidence that there is a need for strengths-based research paradigms is apparent in some family development theories. Family development theory explains events that signify new stages in family life. However, family development theories perpetuate assumptions that there are typical families and typical family stages (Laszloffy 2002). Family stress theory explains the importance of family adaptation and functioning (McCubbin and Patterson 2008) however, family stress theory defines events (such as a diagnosis) as a crisis. Proponents of the neurodiversity movement, would eschew considering a developmental diagnosis a crisis and might be more likely to celebrate the unique strengths of the individual. Health-illness transition theory describes how a diagnosis of one member of the family creates unexpected transitions for other family members (Meleis 2010). However, characterizing a developmental diagnosis as an illness reinforces a deficit-based perspective and suggests families and professionals should seek to cure children with developmental diagnoses.

The Parent Transformational Process Model ([PTPM] Scorgie et al. 2004) stands in contrast to other parent transition theories because the research paradigm is family-centered. In addition to describing parents' process of image-making, meaning-making, and transformation, the PTPM recognizes parents' strengths (Scorgie et al. 2004). The PTPM indicates that the absence of stress is not necessary for parent transformation and that some parents describe becoming stronger, more compassionate and self-defined due to having a child with a developmental disability despite describing the period surrounding diagnosis as traumatic (Scorgie and Sobsey 2000). While the PTPM is family-centered, there is a need to explore developing a transition theory that places families at the center of the transition, rather than the child's diagnosis.

Read for Insights and Analogies

While theory derivation does not require a systematic literature review, we used a modified Critical Interpretive Synthesis (CIS) approach to guide our engagement with the literature. Rather than using a tightly focused research question we used the guiding question: What are parents' needs before and during the diagnostic process? Additionally, we were interested in understanding parents' experiences from a strengths-based perspective. Although CIS is an iterative approach, we will discuss our process in terms of phases. The initial phase of our literature review included a broad-based search of the literature to gain an overall understanding of parents needs surrounding the diagnostic process and transition in general. The second phase of our review focused on the concept of liminality; we reviewed memoirs written by parents of children with a developmental diagnosis in the third phase of our research.

Liminality

The concept of liminality, the state of being "betwixt and between" (Turner 1969; van Gennep 1960) emerged inductively and served as a focus for the second phase of our literature review. We searched EBSCOhost for the terms "liminal" and "diagnosis" in the title or abstract. This search resulted in the identification of 1771 articles published between 1990 and 2015. Disciplines represented in this search include anthropology, political science, art,

Table 1 Categories and representative examples before and at the time of diagnosis

Category	Example	Author
Separation	The experiences of liminality separates individuals from others	(Little et al. 1998)
Awareness	One enters liminality the moment there is a suspicion of a diagnosis	(Forss et al. 2004; Jordan et al. 2015; Little et al. 1998; Mendelson 2009; Nettleton et al. 2014; Timmermans and Buchbinder 2010)
Role performance	Diagnosis seeking may be associated with being a "good parent"; prolonged diagnosis seeking may be an assault to identity and integrity	(Cayless et al. 2010; Crais et al. 2014; Eli 2014; Halliday et al. 2015; Jordan et al. 2015; Mendelson 2009; Moniz-Cook 2006; Timmermans and Buchbinder 2010; Watson 2011)
Uncertainty	Contradictory messages and communication from health care providers, making sense of risk	(Blows et al. 2012; Forss et al. 2004; Jordan et al. 2015; Mendelson 2009; Menkes et al. 2005; Moniz-Cook 2006; Timmermans and Buchbinder 2010)

literature, health, and education. Results from variations of searches combining the terms "liminal", "parent", and "diagnosis" resulted in 62 articles. Topics identified in the search included patient and family experience, parent experience, immigrant/migrant experience, history, children, racial/ethnic/gender status and condition or illness. We extracted data from 22 articles describing empirical research that included examples of individuals' experiences before diagnosis. We identified three primary themes from our review of the literature (a) the individual; (b) tasks; and (c) the environment. Table 1 provides an overview of topics addressed by the articles.

Liminality is a concept originating from anthropological research on ceremonial rituals known as rites of passage. Rites of passage occur throughout an individual's life as they move from one occupation to another and assist individuals as they transition into their next role in life (Turner 1969; van Gennep 1960). Regardless of what the new role is, rites of passage mark social transitions that involve letting go of a previous role, entering a transitional stage and reintegration (van Gennep 1960). The state of being in between roles, or being neither here nor there is known as liminality.

Researchers have used the concept of liminality in studies of patients and caregivers in various health conditions and settings. Watson (2011), found parents experienced ambiguity and uncertainty after the birth of their very preterm infant. Liminality has also been used to describe patients and caregivers' cancer experience (Balmer et al. 2014; Brown et al. 2014; Ho et al. 2014) and other experiences associated with illness and death (Blandin and Pepin 2015). Gibbons et al.'s (2014) literature review on liminality as a conceptual framework for family caregiver rites of passage identified three phases universally experienced by caregivers. An event that results in a need to commit care for a family member or other loved one characterizes the pre-liminal stage. The liminal stage is a period of transition when social roles and relationships change. Uncertainty and suffering characterize this stage. Caregivers assume a new identity and find a new normal in the post-liminal stage (Gibbons et al. 2014).

Parents' narratives

The third phase of our literature review included studying memoirs written by parents of children with an autism diagnosis: (a*) Journey with Julian* (Ballen 2012); (b) *Seeing Ezra* (Cohen 2011); (c) *Following Ezra* (Fields-Meyer 2011); (d) *Unstrange Minds* (Grinker 2007); and (e) *The Horse Boy* (Isaacson 2009). We selected memoirs based on the book's classification as a memoir or autobiography, popularity, and publication date. We used a reading guide to identify content related to parents' descriptions of their identity before, during and after the process of seeking and receiving an autism diagnosis, how parents describe noticing differences in their child development and how parents describe everyday activities.

Source theory: Well-being in Refugee women experiencing cultural transition

We derive our theory from the RWCT (Baird 2012). The utility of the source theory to provide insight in a new field drives the process of selecting a source theory. We selected the RWCT because it specifically addresses the concept of liminality, an experience explicitly described in transition literature (Kralik et al. 2006), in research, and implied in parents' narratives describing their experiences surrounding their child's developmental diagnosis. Additionally, the RWCT addresses transition using language that is like parents' descriptions of the diagnostic process, which we describe in the theory derivation section.

The RWCT is a situation-specific theory resulting from studies of refugee women who resettled in the United States (Baird 2012). Three themes serve as the foundation for the theory: (a) liminality: living between two cultures; (b) self-support: standing on our own; and (c) hope for the future (Baird 2012; Baird and Reed 2015). The concept of

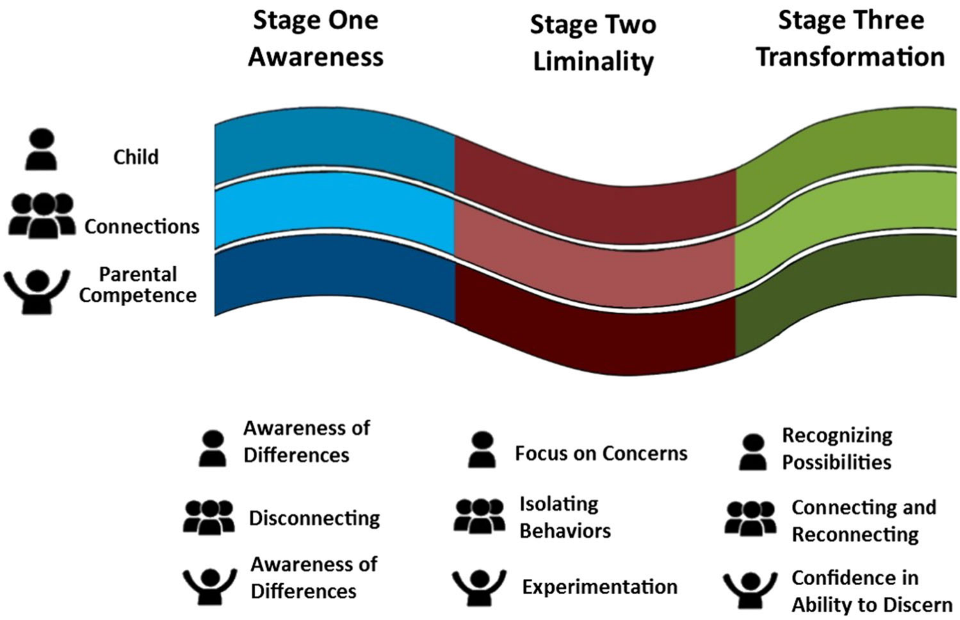

Fig. 1 Broski and Dunn's strengths-based theory of parental transformation

liminality underscores the importance of understanding strengths at every phase of transition, particularly when families feel they are in between two worlds (Baird and Reed 2015).

Derived theory: Strengths-Based Theory of Parental Transformation

The purpose of Broski and Dunn's STPT is to provide a framework to conceptualize parents' experiences while they wait for a developmental diagnosis for their child. In the source theory, individuals' experience a change in culture resulting from a change in geographic landscape (Baird and Reed 2015). In the derived theory, parents' experience a change that occurs in response to a shift in the parents' mental landscape. Mental landscape is a metaphor that refers to individual's cognitive representation of their environment (e.g., Chaney 2010; Golledge 1991; Ramsey 2016).

The STPT (Fig. 1) references three transition phases: (a) initial awareness of the new landscape, (b) rites of passage in the new landscape, and (c) transformation of self. Within each of the stages, we use three domains to describe parents' experiences while they wait for their child's diagnosis. We refer to these domains as the three C's of parent's mental landscape. The first C in the mental landscape represents the child. Parents' awareness of their child's behavior or functioning characterizes the child domain. The second C in the mental landscape is connections. Parents' experiences with friends, families, and professionals characterize the connections domain. The third C in the mental landscape is competence. Parents' concerns about fulfilling social roles characterize the competence domain.

Initial awareness of differences in the mental landscape

In the source theory, the first phase of individuals' transition is separation from their culture of origin and identity, which leads to confusion and then awareness of the new landscape. In the derived theory, the first phase is parents' initial awareness of differences in their mental landscape. The mental landscape is the mental model individuals use to understand and navigate their lives; it reflects an individual's identity by referencing cultural values, personal preferences and geographic locations (Golledge 1991). The memoirs included descriptions of parents feeling they had traveled to a new world. For example, Isaacson (2009) questioned if his son's diagnosis might not signal shutting down his life, but instead "be the gateway to the greatest adventure of all" (p. 48). Cohen (2011) argued that parents should not be judged "for the ways they've found to cope with this alien world of being a special needs family" (p. 137). Ballen (2012) described his experience as a "journey through the world of autism" (p. 1). Fields-Meyer (2011) described how shopping with son "is like landing in a foreign country, or the moon" (Chapter 14, section 2, para 13).

Child domain: Awareness of differences In the initial awareness phase, parents notice differences in the child's behavior or development (Ballen 2012; Isaacson 2009). Ballen (2012) described his wife's awareness of differences, "I will never forget the determination in Martina's voice. She was the one who first began to think about this" (p. 2). Some parents described making lists of differences in their child's behavior. Fields-Meyer (2011) suggested his wife might be trying to make sense of chaos by compiling an inventory of their son's traits (Chapter 1, section 2, para 4).

Family, friends or acquaintances may trigger parents' awareness of differences (Cohen 2011). False positives from newborn screening tests can also initiate parents' concerns about their child's development (Timmermans and Buchbinder 2010).

Connections domain: Increasing distance In the autobiographies we reviewed, all parents described a sense of distance or isolation from the world. In some cases, parents referenced their child's solitary behaviors. When a child's behavior does not appear typical, parents may not know what to tell people about their child's behavior (Midence and O'Neill 1999) which can result in disruptions in their connections with others (Maciver et al. 2011). Parents also describe challenges in their relationship with their child when efforts to be close to the child do not seem to be successful (Desai et al. 2012; Farrugia 2009). Confusion surrounding how to respond to their child's behavior in social settings creates barriers to social connections in the new mental landscape. Some parents report their child's sensory patterns challenge the parent's ability to socialize. Cohen's memoir (2011) illustrated why she stopped going to social events and reaching out to her friends. Cohen described going to a birthday party with her child, but when all the children started singing happy birthday, she needed to take her child out of the house to accommodate her child's sensory needs. Cohen describes feeling childish, frustrated and alone as she looks in at the party from the outside, watching the other parents socialize while she stands outside with her child.

Parents may report strained connections when friends or family members seem not to understand what the parent is going through (Farrugia 2009; Midence and O'Neill 1999). Some of the memoirs we read echoed this sentiment. Cohen (2011) describes how her concerns about her child's development affected her relationship with her husband. "I cannot keep burdening Michael with these worries…. Twice he's asked me 'Should I be worrying?' No!… Because I can't have Michael overly concerned. If he worries with me, who will pull me back? Who will keep us from falling more deeply into this endless fear" (p. 52).

Competence domain: Seeking confirmation Individuals' ability to see and portray themselves as competent is an important aspect of self-identity. For parents, this includes parenting in ways they believe in and that others validate (Christiansen 1999). In the initial awareness phase, parents report seeking confirmation with other parents or professionals to allay concerns about their child's behavior or development or to validate their observations (Tait et al. 2016). For example, Cohen (2011) describes her response to therapists when they asked why she had her child evaluated; "I'm supposed to…to be a good mom, I have to help him" (p. 26). Similarly, Isaacson (2009) describes responsible parenting as the reason he and his wife contacted the state's early childhood intervention program (p. 12).

Rites of passage in the new landscape

A central concept emerging from the theory of RWCT is liminality (Baird and Reed 2015). The liminal stage occurs when individuals are on the threshold of a new way of life and in between social roles (Turner 1969; van Gennep 1960). Baird and Reed (2015) identified liminality as an important process in transition as well as a conundrum: "Someone experiencing liminality can feel disconnected and uncomfortable yet have the capacity for growth and transformation… There is a creative potential in liminality that can lead to opportunities to change and reformulate the self" (p. 31).

Child domain: Focus on concerns In this phase, parents' awareness of differences in their child becomes a primary focus. Even if the child does not have a diagnosis, parents may begin intense routines to help their child. For example, a primary storyline in *Horse Boy*, Isaacson (2009) focused on his family's decision to travel to Mongolia to meet with shamans to help their son, "I wanted something more radical, something miraculous. Would taking him to the horses and shamanic healers of Mongolia provide that…. I could not get the idea out of my head" (p. 53). Cohen (2011) described concerns that she recognized as contradictory, "I worry that it's not enough, and I also worry that it is too much, that the therapies are stressing his tiny, not-even-two-year-old world" (p. 40).

Connections domain: Distance and isolation During this phase, what begins as increasing distance in relationships can lead to isolation. Because parents' new mental landscape does not seem to match a normal way of life, parents can feel disconnected or isolated from their friends and family. Parents who don't understand which direction to turn may feel disconnected from community care systems (Farrugia 2009). Parents may also feel disconnected if their child does not have a diagnosis, "…one of the biggest things that I've found personally not having a diagnosis is that I do not belong anywhere…. with my child being undiagnosed" (Pelentsov et al. 2016). Cohen (2011) described the rift she felt with other parents, "more and more I struggle to connect with parents who have only typical children. Sometimes I feel dumbly angry at them; sometimes I envy them" (p. 137). Isaacson (2009) described how he felt disconnected from others when people avoided his child; "he'd writhe on the ground and babble…..climb the fences—then tantrum violently when prevented, often vomiting or shitting his pants at the same time….other parents and visitors would cluck disapprovingly and move away from the noise" (p. 22).

Competence domain: Searching for answers and experimentation During the rites of passage phase, parents may experiment with popular cures or other remedies from public sources (Armstrong 1995; Timmermans and Buchbinder 2010). Experimentation during liminality is associated with the process identity reconstruction (Beech 2011). Experimentation may be a strategy parents use within the new mental landscape to learn its characteristics and limits. During this phase, parents' may expend a great deal of energy to fulfill their definition of what it means to be a good parent in their new role as a parent of a child with a developmental disability. For example, Cohen (2011) described searching for schools, diet supplements, and new strategies to encourage her son to eat. She described her need to "be running, moving, searching, finding" (p. 122). Cohen also described trying things she did not believe in; "driving through a town…. I stop in and see a psychic. Do I believe in psychics? Not really. But psychics have crystal balls, and I desperately needed one right now….I need to know if my son will be okay" (p. 112). Ballen (2012) described how trying to command his child to stop flapping or holding his child's shoulders did not help to reduce stimming behaviors. Ballen goes on to describe looking for opportunities to allow his son to move around in self calming ways when his son's movements would not be disruptive in public places. Eventually the family discovered having pen and paper available for his son to draw on could help keep his son calm (pp. 4–6). This trial and error approach

Transformation of self in the new landscape

The source theory indicates that despite individuals finding themselves in an unfamiliar place, replete with ambiguity and loss, the third phase of cultural transition provides creative potential (Baird and Reed 2015). The source theory describes this as standing on our own two legs and having hope for the future. In the derived theory, parents' transformation occurs when they experience opportunities to grow and redefine themselves, their child and their family. All the memoirs we reviewed describe settling in and becoming at home in a new world. We use Baird's (2012) conceptualization of well-being to inform our conceptualization of self-transformation:

> A process measured over time in which one has adequate resources to meet basic physical, emotional, social, and spiritual needs. An individual with a sense of well-being experiences peace of mind, acceptance of life as it is presented, a sound physical condition, and a state of emotional and spiritual balance that leads to the belief that life is worth living (p. 255).

In our reading of parents' memoirs, we found many instances of parents' describing a new sense of well-being. During this phase, parents' express understanding of their child's differences and unique strengths. Parents describe discovering new ways to see the world and often credit their child for teaching them important life lessons. It appears that parents embrace a wellness approach to parenting, an acceptance of life as it is. Cohen's (2011) recognition that being a good parent is not the same as needing to be perfect is an example of transformation and well-being:

> The great feat in Ezra's and my story is that I do nothing. Finally, I do nothing. I let Ezra be who he is, and I let me be me, with all our limitations. I let Ezra show me that he doesn't need me to do anything but love him. I let him show me that I will be uncomfortable sometimes. I'll feel helpless. In our story, life doesn't suddenly become easy…that's just our lives together. There is no tragedy here (p. 278).

Child domain: Recognizing possibilities In the early awareness phase, parents may itemize their child's weaknesses or compare their child to other children. Over time, these behaviors appear to diminish and parents begin to focus on their child's strengths rather than comparing their children to others (Grinker 2007). Parents describe spending more time enjoying their children and less time thinking about problems (Lewis et al. 2010). Parents describe finding new possibilities regarding their child's differences, such as how well their child copes with medical procedures (Carmichael et al. 2015). In his autobiography, Fields-Meyer (2011) reflects on an experience watching his three-year-old son walk ahead of him on a private road. He describes feeling fearful about his son's lack of awareness that he was getting too far ahead of his dad. Years later, Fields-Meyer summarizes his transformative experience:

> This is the story of what happened in the 10 years following that summer, a decade that has delineated a personal journey, beginning in darkness, winding through desperation, fascination, love and ultimately a sense of awe for our unique, exceptional son…. I have watched from an increasing distance as he takes a path all his own…. Long ago, I made my choice: to follow Ezra and to watch, in awe and mystery, as my son makes his own unique way in the world (Prologue, para 11–12).

Grinker (2007) described coming to see his child in a new light. “At the end of the day, when I tuck her in, she’s not a case of autism, or even a child with social deficits and language delays. She’s simply my daughter” (p. 35). Ballen (2012) described his son as having “something to contribute to this world. His creativity and imagination are immense and seem boundless” (p. 180).

Connections domain: New relationships Research on family resilience indicates parents who have experienced challenges may participate in activities they perceive will help others. These activities may involve making connections with people they would not have met otherwise. It appears parents perceive that their altruistic actions honor their child or other family members who have shown them support (Lietz 2011). For example, a parent participating in a fundraiser for a camp for children with autism, described her experience doing stand-up comedy with other parents:

> For months prior to the event we dissect our lives and bare our souls to a group of people who become our tribe…. So for the past 3 years, and into the unforeseeable future, ‘An Evening with the ‘Rents’ has become a part of who I am. I overcame my anxiety, stood up on that stage and shared my life, thoughts, and feelings with hundreds of strangers. And you know what? They laughed with me and they loved me for who I am and for what I am becoming. But even more importantly, I feel like I gave something back in return. I hope with all my heart that I have encouraged someone who was in the same place I was. I hope I have reminded them of who they are and inspired them to step out in faith. I hope that I planted a seed that will create new growth and joy in their life (Ray 2017, para 2–5).

Throughout her memoir, Cohen (2011) described strained relationships with her family and other parents, in the end, she describes finding comfort in her relationships with others, “the other parents and I discuss these issues…. it is such a relief to have other mothers to talk with, mothers who understand. After all this time, I feel seen by other people again” (p. 238). Isaacson (2009) described how his journey led to him starting a program for children with an autism diagnosis.

> Upon our return from Mongolia, I managed to raise money to buy land to start an equestrian program for PDD kids. Fifteen acres of gorgeous land….It is a place where children can play and ride and be happy….Part of the proceeds from your purchase of this book will enable us to offer scholarships to families who cannot afford equine therapy (p. 349).

Competence domain: Confidence in ability to discern Parents of children with unidentified differences report high motivation to obtain a diagnosis when their child is young, but the desire to confirm a diagnosis can fade over time (Rosenthal et al. 2001). Parents also describe gaining the skills they need to get things done for their child, such as getting appointments and services for their children “I’ve had to learn to be that sort of person” (Lewis et al. 2010). In the third stage of STPT parents recognize their wisdom (Ballen 2012; Cohen 2011; Fields-Meyer 2011; Grinker 2007; Isaacson 2009) and consider sharing their insights with others (Ray 2017).

Grinker (2007) is philosophical about his transformation, “I am not a religious person, but there is something profoundly meaningful, if not spiritual, about being the father of a child with autism that has pushed me to consider lofty, abstract principles like truth, beauty, and goodness” (p. 23). Fields-Meyer (2011) describes changing his thinking about his child’s disability. Instead of viewing his son’s challenges as something to get past to get on with life, “I eventually learned that this is life. This is what life is. It wasn’t about finding the right expert for my child; it was about learning to be the right parent” (Prologue, section 2, para 1). Ballen (2012) characterizes his transformation regarding roles that have meaning for him, being a dad and work. “Julian has inspired me to be a better man and given me clarity on what it means to be a father…. definitely the best job I’ve ever had” (p. 42). Isaacson (2009) describes discovering new ways to think about work and leisure activities, “as for me, freed now from riding only as part of Rowan’s therapy, I found a whole new direction with horses…. I put my insecurities aside, started training…. I began to discover my own inner horse boy” (p. 347).

Summary of the STPT

The memoirs we reviewed described awareness, liminal stages and moving beyond a state of ambiguity. While these parents described finding new insights and meanings, some researchers suggest there may be situations such as with a cancer diagnosis in which individuals’ experience sustained liminality (Little et al. 1998). Although parents frequently described gaining insights during a prolonged liminal state, there were also indications parents could experience a kind of instant insight, in other words, an ability to gain insight without a lengthy struggle with ambiguity. For example, Fields-Meyer (2011) described an experience toward the beginning of his memoir when a therapist suggested the family needed time to grieve for the child his son did not turn out to be.

> I realize something: I am not grieving. In fact, I feel no instinct to grieve…I'm not going to grieve. I am sure she thinks I am deluding myself. I know the truth. The one statement (that he needs time to grieve) has done more good for me than all the play therapy, than all the listening, all the advice. It has forced me to find and bring out something within myself. I feel full of love—for the boy who lines up the dinosaurs on the porch…My answer will never be to mourn. It will be to pour love on my son, to celebrate him, to understand, to support him, and to follow his lead. (Chapter 1, section 3, para 27–30)

Discussion

The purpose of this paper is to describe a strengths-based theory of parents' transformation before their child's developmental diagnosis. Parents' unanticipated journey frequently involves developing awareness of changes in their mental landscape. We describe the STPT within the context of parents' developing awareness of those changes. The process of theory derivation initially involves developing a model without immediate knowledge of its accuracy.

Research on parents' experiences before their child receives a developmental diagnosis tends to focus on parents' experience with the diagnostic process and uncertainty surrounding their child's development. This focus inadvertently reinforces a medical model perspective. Parents with concerns about their child's development have experiences in addition to the diagnostic journey that contributes to the family and child's overall strengths and development. Ecological models of disability indicate that disability is a function of the interaction of the individual and the environment, rather than a deficit that resides in the individual (e.g., Pope and Brandt 1997; Schalock et al. 2010). However, research and interventions that focus on parents' anxiety or stress associated with having a child with a developmental diagnosis suggest limitations reside within the family. While the diagnostic process focuses almost exclusively on the child, parents have experiences throughout the diagnostic process that involve constructing new images of their children, themselves and their lives (Scorgie et al. 2004). Parents often associate a potential developmental diagnosis with images of disability that have formed through societal portrayal and beliefs about disability (Scorgie and Sobsey 2000). The information parents receive at this time shapes images parents create of their child (Taanila et al. 2002). Some parents live in a state of tension created by a need to construct hopeful child and life-trajectory images during pessimistic reports about their child (Steele 2000). The need to balance joy and sorrow may cause parents to limit thinking about the future, and focus on on the present (Kearney and Griffin 2001). Not only do parents' experiences surrounding diagnosis influence image-making (Scorgie et al. 2004) reports and feedback from hospital personnel, agency workers, educators, extended family members and friends can shape parents' response to their child's diagnosis.

Future studies should explore how parents perceive and define the different stages of transition and should explore ways in which parent develop awareness in their mental landscape. Studies should explore using the STPT as a cognitive tool to assist parents in identifying unexpected opportunities to recognize insights about their child, develop a stronger sense of themselves as parents and consider new possibilities for their family. Because implementing strengths-based practice requires clarity about the approach, including operationalizing the constructs of the theory (Staudt et al. 2001); there is a need to delineate how parents and providers determine the end of one stage and the start of the next phase. There is a need to determine what aspects of parents' experiences are not part of parents' transition experience. Future testing should empirically examine domain attributes and definitions. Evaluation of the theory should include examining the relevance of STPT to the delivery of family-centered care while families wait for a diagnosis.

Longitudinal research on parents' experiences surrounding their child's developmental diagnosis is complex, multifaceted and frequently misunderstood (Pedersen et al. 2015). Future research should explore if families benefit from reflecting on their experiences through a strengths-based framework. Additionally, future studies should investigate whether the STPT may contribute to implementing family-centered practice in clinical settings. Finally, studies should focus on determining if the concept of liminality, which provides a possible explanation for how and why parents experience ambiguity in the midst of transition, may provide a useful framework for parent education.

Limitations

We recognize several limitations of our methods and theory. CIS is useful when the purpose of the literature review is to generate theory. However, the iterative nature of this process is guided by emerging theory. Therefore, many aspects of the literature search would be difficult to reproduce. While we used multiple methods to triangulate evidence supporting the STPT, the first author is a parent of a child with a developmental diagnosis and while we were intentional about bracketing, we recognize the author's experience has the potential to bias our findings. Another potential for bias is the use of published parent memoirs. It is possible that parents who continue to struggle with transition would not be inclined to publish their stories or may not have the resources to share their stories in such a public way, so it is possible that these parents' voices could potentially be under-represented in popular press publications.

Improving support for children is best accomplished through family-centered services that recognize families' strengths. Some families may not receive a diagnosis for several years, while other families may never receive a diagnosis. We propose further testing of the STPT to determine its utility to provide an alternate explanation for providers and parents to consider. While we recognize waiting for a developmental diagnosis generates uncomfortable feelings of uncertainty, a theory of transformation provides an opportunity for parents and providers to discuss the future in a realistic yet hopeful manner.

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Compliance with ethical standards

Conflict of Interest The authors declare that they have no conflict of interest.

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

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