Journal of Religion & Society (JR&S)
Available Online:
https://islamicreligious.com/index.php/Journal/index
Print ISSN: 3006-1296Online ISSN: 3006-130X
Platform & Workflow by: Open Journal Systems

Psychological Well-Being of Mothers of Children with Developmental Disabilities in Punjab: A Qualitative Inquiry

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Abstract
In the field of special education and mental health research in Pakistan, the psychological health of mothers of children with developmental disability is a highly important but little studied area. Punjab mothers who have children with intellectual disabilities, ASD, cerebral palsy, Down syndrome and related neurodevelopmental conditions have the heaviest burden of care in a sociocultural context of gendered care, disability-related stigma, weak professional support networks and the lack of formal psychological support for mothers. The methodology used in this qualitative study is Interpretive Phenomenological Analysis (IPA) in an interpretive paradigm of developmental psychology lived experiences of mothers of children with developmental disabilities in Punjab. In-depth semi structured interviews and focused group discussions with purposively selected mothers in government special education institutions of Punjab were conducted to generate data. Based on the conceptual framework of the Multidimensional Model of Psychological Well-Being proposed by Ryff, the thematic analysis demonstrates a complex psychological trajectory for Punjabi mothers, ranging from severe grief and chronic sorrow, to social marginalization and identity disruption, together with an impressive capacity for resilience, spiritual meaning-making, positive personal growth, and intense advocacy for their children's rights and dignity. The study highlights key structural, cultural and institutional barriers to maternal psychological well-being in the setting of Punjab and recommends a package of policy and programmatic interventions that will help establish psychologically supportive services, culturally appropriate integration of mental health services within the overall framework of special education, and community-based infrastructure to support maternal psychological well-being.

Keywords: *psychological well-being, mothers, developmental disabilities, Punjab, Ryff's multidimensional model, interpretive phenomenological analysis, qualitative inquiry, caregiver burden, chronic sorrow, resilience, Pakistan, special education, mental health*

1. Introduction
The many facets of human life that developmental disability affects are perhaps best captured in the intimate, long-term, and psychologically significant relationship between the mother who becomes primary caregiver of a child whose developmental path is very different from the norm. The developmental disability journey of a child (or the realization of developmental delay for an infant or toddler) signals a course of care that is qualitatively distinct from the care needed by parents of children without developmental delays in its emotional, practical, social and identity requirements (Hastings & Taunt, 2002). Demands are general in their scope, but are highly individualized in their content and intensity

according to the sociocultural, economic and institutional contexts in which mothers live and care.

The sociocultural environment of maternal care for children with developmental disabilities in Punjab, Pakistan, is a complex interplay of factors that significantly heighten the psychological burden of caring. In Pakistani household structures, mothers are responsible for the care of children with disabilities, with primary and often exclusive responsibility, despite the complexity of the child's needs and the availability of professional support (Mirza & Shamsi, 2018). The stigma associated with disability, conveyed through community reputation and perceived as a personal and familial sin or defect, exacerbates the challenges of providing care and can cause social isolation and shame. The disjointed and poorly resourced special education system provides little infrastructure of respite, psychological support or empowerment for mothers, and mothers must deal with their children's developmental issues without adequate professional guidance or community support (Saeed et al., 2020).

The psychological health of these mothers does not exist on the outskirts of the design of the special education system in Punjab, but is a key factor in the outcomes of child development, functioning of the family system, and the ability of these mothers to advocate effectively for their children's access to education. Across diverse national and cultural contexts, research findings have been consistent: maternal psychological distress is linked to poor quality parent-child interaction, low responsiveness to the child's communicative and emotional cues, and low involvement with the child's formal school-based education, which have direct developmental implications for the child (Singer, 2006). Investing in the psychological health of mothers with developmental disabilities in Punjab, thus, is an investment in child development and family resilience, as well as the efficiency of the special education system.

However, to the best of the authors' knowledge, there has been very little systematic qualitative research that specifically focuses on the psychological wellbeing experiences of Punjabi mothers of children with developmental disabilities. The somewhat limited Pakistani literature around disability and families has been predominantly focused on quantitative measures of family/caregiver stress, leaving out the phenomenological richness of a woman's life and well-being as it is lived and constructed by the women who live it. (Khanna et al., 2011) This study aims to fill this gap by conducting a qualitative phenomenological approach to the exploration of psychological well-being in the mother, based on Ryff's Multidimensional Model of Psychological Well-Being and supported by an extensive review of the literature. This article is structured as follows, in section 2 the theoretical framework is presented. A review of the literature is included in Section 3. The research methodology is detailed in Section 4. The Thematic findings are included in Section 5. Section 6 discusses findings. Section 7 identifies limitations. Section 8 presents recommendations. Section 9 concludes.

2. Theoretical Framework: Ryff's Multidimensional Model of Psychological Well-Being

The current study uses the Multidimensional Model of Psychological Well-Being (MMPWB), first described by Carol D. Ryff in a 1989 research paper published in the Journal of Personality and Social Psychology and since developed into a multi-layered model that has been studied and validated in various populations and across different cultures (Ryff, 1989; Ryff & Singer, 2008). Ryff's model has grown out of a critical investigation of the hedonic tradition in well-being research, which views well-being as synonymous with positive affect and absence of negative affect, as well as the dominant

clinical approach of defining psychological health as the absence of pathology. Based on the philosophical concepts of Aristotle's "eudaimonia," Maslow's "hierarchy of self-actualization," Erikson's "social and psychosocial development theory," Allport's concept of "maturity," and Rogers' fully functioning person, Ryff created a positive, multi-dimensional model of psychological well-being that integrates both the negative challenges and the positive realizations of psychological flourishing.

The model outlines six core areas of psychological wellbeing which are considered to be separable and fundamental aspects of psychological flourishing. Self-acceptance is defined as a positive attitude toward the self, an acceptance of the self, an acceptance of multiple aspects of the self (qualities and limitations) and a positive self-evaluation of one's life experiences. The process of self-acceptance is often compromised in mothers of children with developmental disabilities because of guilt, self-blame, and internalization of societal attributions making disability the result of maternal failures (Ryff, 1989). Positive relations with others includes warm, trusting and satisfying relationships; caring for others' well-being; and ability to have deep empathy, affection and intimacy. Stigma-based isolation and intensive caregiving time have been well documented as the main drivers of the impact of disability caregiving on the social relationships of mothers of children with disabilities (Emerson & Hatton, 2014).

Autonomy is a self-regulating, self-determining, self-independent attitude to behavior, resistance to social pressures and self-evaluation on personal standards. Mothers in patriarchal family contexts in which the daily lives are structured around the care responsibilities, often have limited autonomy, which has a significant impact on this dimension of their well-being (Mirza & Shamsi, 2018). Environmental mastery is the ability to select or design environments that are appropriate for one's psychological state(s) and to control that environment in an efficient manner. Environmental mastery is undermined by a lack of institutional accessibility, professional gatekeeping, and financial constraint for mothers who struggle to access the special education system in Punjab in the context of its under-resourced nature (Akhtar & Yasmin, 2011).

The purpose in life consists of: belief in the purpose and meaning of life, having goals and intentions, and feeling that life is meaningful in the past and present. Raising a child with a developmental disability is often a life-changing event and can result in meaningful purpose or paralyzing dispiriting lack of purpose when social and career supports are either lacking or lacking in quality (Ryff & Singer, 2008). A sense of growth, a sense of openness, a sense of becoming what one can be are all elements of personal growth. One of the most interesting results in the qualitative literature on mothers of children with disabilities is that many describe personal growth which includes increased empathy, changed priorities, strengthened advocacy skills, and a greater focus on human value as unexpected gifts of their caregiving experience (Hastings & Taunt, 2002). The specificity of the framework of the study by Ryff is that it can accommodate both the negative and positive aspects of maternal well-being experience, allowing for the recognition of both the intensity of suffering and the strength of maternal resilience, without erasing one into the other.

3. Literature Review

The international literature dealing with the psychological health of mothers of children with developmental disabilities is very large, and though there are methodological differences, there is a consistent finding in this literature of significantly higher levels of psychological distress among these mothers than among typically developing mothers. Singer (2006) reviewed 19 comparative studies and found significantly greater clinical depression rates among mothers of children with developmental disabilities, and effect

sizes that suggest a moderate clinical depression risk increase among mothers of children with developmental disabilities. Emerson and Hatton (2014) did a comprehensive review of health disparities among families of children with intellectual disabilities and found that the mental health burden of disability caregiving increases with socioeconomic disadvantage, social isolation and lack of service support which is clearly evident in the disability caregiving context in Punjab.

Although the narrative of parenting a child with a developmental disability is one of deficits, Hastings and Taunt (2002) conducted a seminal review that documented the extent to which a sizable number of parents report positive effects of caregiving on their lives (such as increased family cohesion, expanded empathy, and transformed value systems), lending empirical support to the capacity of the multidimensional framework to capture both the distress and growth aspects of the parenting experience. In the context of autism, Bayat (2007) built upon this positive psychology approach by reporting on families' resilience and family growth in culturally diverse samples, and provided the theoretical underpinning of posttraumatic growth for disability caregiving families.

In the Pakistani and South Asian situation, Khanna et al. (2011) found that the health-related quality of life (HRQOL) of primary caregivers of children with ASD (autistic spectrum disorder) was significantly lower in South Asia, especially for the mother who is the primary caregiver in Pakistan. Mirza and Shamsi (2018) offered the most context-specific analysis of gendered caregiving and disability in Pakistan, and cited the exclusive burden of caregiving to mothers in the patriarchal structure of households and its impact on women's occupational involvement, social interactions, and psychological health. Miles (2002) studied the phenomenon of cultural constructions of disability in South Asian Muslim communities, noting the many descriptions of developmental disability in religious and supernatural terms, and how these descriptions affect the way people seek help, manage stigma, and interpret the experience of disability and their coping strategies.

The chronic sorrow framework was developed by Olshansky (1962) and later elaborated in the qualitative disability literature is an important conceptual lens for thinking about the repeated grief that mothers of children with developmental disabilities experience with developmental transitions in which the typically developing trajectory of the child's peers diverges from his/her own. In a qualitative study Kearney and Griffin (2001) described parents' experience of having a child with a developmental disability, illustrating how joy and sorrow can coexist in the parenting experience, in a manner that is directly connected to Ryff's multidimensional framework's ability to hold both positive and negative dimensions of well-being. In relation to the Ryff model of personal growth and purpose, Scorgie and Sobsey (2000) documented qualitative data on the transformational outcomes of parenting children with disabilities, including personal growth, improvement in relationships, and the development of advocacy, which are all relevant to the positive changes in the disability caregiver's well-being landscapes.

Multiple studies indicate that one of the most significant service gaps in the special education system in Punjab which impacts the maternal psychological well-being is the lack of informal respite care, caregiver counseling and peer support system (Akhtar & Yasmin, 2011). Folkman (1997) laid the groundwork for conceptualizing positive psychological states and meaning-focused coping as important coping resources in coping with the chronic stress of disability caregiving, which provides insight for how Islamic spiritual frameworks, peer connection and purposeful advocacy are coping resources for Punjabi mothers identified in the qualitative findings of this study. The multilevel nature of disability stigma, described by Corrigan (2007) as self, social, and institutional stigma,

offers a conceptual framework to understand how disability stigma and the psychological difficulties it creates with disability caregiving are further exacerbated in a cultural context in Punjab.

4. Research Methodology

This research is based on an interpretivist research paradigm, which emphasizes understanding the psychological experiences of human subjects, in this case, mothers of children with developmental disability, in a way that goes beyond objective, external measures and into the subjective meanings and ways of making sense of one's life as captured in interpretative frameworks and culturally embedded understandings (Creswell, 2013). The epistemological approach adopted is that of constructivism: knowledge concerning the psychological well-being of Punjabi mothers is not seen as an objective reality to be observed, but rather created in the interpretive process of qualitative inquiry, as a result of the interpretive dialogue between the researchers' theoretical and professional constructs and the participants' experiential accounts.

The focus of this study on psychological well-being makes the use of the interpretivist paradigm particularly applicable for several reasons. Psychological well-being, as Ryff's own model implies, is highly multidimensional and subjectively defined, and it is defined from within, and shaped by the individual's personal reflective engagement with her life, relationships, and sense of purpose. Second, the nature of maternal well-being in Punjab is culturally shaped and culturally specific, as well as being socially constructed, and not necessarily 'culture free' or universal, since it is influenced by Islamic religious contexts, collectivist family norms, disability stigma and the gendered nature of caring responsibility. This culturally specific experience of well-being must be interpreted with what qualitative instruments can only access culturally: the meanings that make up the well-being experience (Lincoln & Guba, 1985).

IPA is phenomenologically orientated, focused on understanding the lived experience as it presents in consciousness, and also recognizes the interpretive nature of research inquiry, that is, the researcher's own theoretical knowing, professional history, and personal perspectives always and necessarily affect the way in which participant accounts are analyzed, and that this shaping needs to be recognized, examined, and made explicit by using reflexivity, not by trying to "neutralize" or suppress it with claims of methodological neutrality. In the context of the culturally specific world of disability caregiving in Punjab, a world with which all the members of the research team have had their own interactions and relationships, this reflexive and interpretive approach to the research process is not only methodologically suitable, but epistemologically necessary (Smith et al., 2009).

Typically, IPA is used with small purposive samples of participants who have a shared, large experiential domain, in which each individual's experience is analysed in detail and then extended to a more theoretically generalised cross case analysis. The homogeneous sampling approach (i.e., sampling across cases and themes based on the key experiential characteristic of the participants – primary maternal care of a child with a developmental disability in Punjab) ensures that the cross-case comparisons and theme development are based not on a distantly common but on a truly common experiential terrain which eliminates the masking effect caused by differences in life circumstances between the various life histories in the sample (Smith et al., 2009).

4.1 Study Setting and Context.

The study has been carried out in the setting of government Special Education Centres (SECs) in three districts of Punjab that are of different geographical locations: Lahore (metropolitan), Multan (secondary city) and a district level site in the central area of

Punjab. The multi-site design was selected to represent the diversity of institutional settings, location of care, and socioeconomic circumstances prevalent throughout the province of Punjab in terms of the experience of maternal care. The predominantly government-based nature of the SECs as the main point of formal institutional interaction between mothers of children with DD and the government special education provision in Punjab, and the accessibility of the sample of mothers whose caregiving experience takes place in the institutional environment of government special education provision in Punjab, made them the most appropriate recruitment settings.

4.2 Participants and Sampling

The sampling was purposive homogeneous sampling, the most suitable sampling method for an IPA, as it focuses on those that have a common experiential feature and can be expected to offer information-rich descriptions of the phenomenon being described (Patton, 2002). The criteria for selection for this study were purposive, meaning that: (a) the mothers were the primary caregivers of a child currently attending a government special education center in Punjab; (b) the child had an official diagnosis of intellectual disability, autism spectrum disorder, cerebral palsy, Down syndrome, hearing impairment, visual impairment, or a combination of these conditions; (c) the mothers had cared for their children for at least two years, providing a sufficient depth of experience for phenomenological questioning; and (d) the mothers were willing to participate in audio-recorded in-depth interviews and, where applicable, focused group discussions.

Twenty mothers participated in the study at the three recruitment sites. Children ages 3-15 years and participants ages 26-48 years. Sample included diversity in terms of educational level (no formal education to intermediate level qualification), socio-economic status (lower to lower middle income households), disability category of child (ASD, intellectual disability, cerebral palsy, Down syndrome, hearing impairment, and multiple disabilities), and length of time of being a caregiver (2 to 13 years). The internal diversity of the purposively homogeneous sample of all primary maternal caregivers in government SEC contexts, allows for the identification of common structures of experience within the sample and also allows for the identification of differences in the lived experience of each individual well-being dimension in a negotiation process (Smith et al., 2009).

Experiential saturation was reached by continuing sampling until no further themes emerged or meaningful variations in the experiential accounts of the six dimensions of well-being being explored were found in additional interviews. Experiential saturation is generally accomplished using fewer subjects than other traditions of qualitative research, as IPA demonstrates a trade-off between depth of idiographic analysis and breadth of thematic coverage (Smith et al., 2009). Experiential saturation was determined after 19 interviews and was confirmed with the 20th interview, as in this interview no new phenomenological content was introduced.

4.3 Data Collection Methods

Two qualitative data collection methods were used, complementary to each other. The key and main approach used was individual in-depth semi-structured interviewing, which is typical of the IPA methodology which focuses on the detailed, idiographic analysis of individual experience. Twenty in-depth interviews with one participant each were conducted. Interviews were all conducted in Urdu at participants' preferred location, frequently the homes where they lived with their family, thus allowing for data collection in a contextually situated way, respecting the maternal well-being experience as most often shaped in the domestic caregiving space. Interviews averaged between seventy-five and

one hundred and ten minutes and were recorded on audio tape with the consent of the interview subjects.

The interview guide aimed to encourage participants to explore their psychological well-being experience in an open way, and to not influence participants' reports of their experience with psychological well-being using the language or categories of the theoretical framework. The guide began with a broad opening invitation that invited participants to respond to the question: 'Could you tell me what your life is like as the mother of [child's name]?' This was followed by experiential probes that addressed the six dimensions of well-being: self-acceptance (How do you feel about yourself as a mother? How do you feel about yourself as a woman?); positive relations (How are your relationships with your spouse, family, and friends?); autonomy (What is your life for? What gives you a sense of direction?); environmental mastery (How do you feel competent in meeting the needs of your child? How do you feel competent in meeting the needs of the services you use?); purpose in life (How do you feel you have changed as a person because of the experience?); and personal growth (How do you feel you have changed as a person because of the experience? To encourage elaboration and enrich the phenomenological quality of participant accounts, follow-up probes were used throughout, such as 'Can you say more about that?', 'What did that mean to you?', 'Can you give me an example?', (Kvale & Brinkmann, 2009).

The second technique was the focused group discussion. Participants were selected for three focused group discussions, held at each recruitment site, with between 6 and 7 participants at each. The FGDs were held in Urdu and each session lasted about an hour and a half, and were audio-recorded along with additional field notes of the researcher. Though IPA was a methodology that focused on the individual, the FGDs were used as a complementary methodology for exploring the social and relational aspects of the maternal well-being experience that is more readily manifested in group settings, where mothers get to experience their well-being in the company of other mothers in a similar situation. The FGDs focused in particular on social relations, the collective meaning-making elements and the community stigma and peer support aspects of well-being experience that lend themselves to group discussion. The individual interview transcripts (Morgan, 1997) became the primary data for the IPA and data from FGDs were used as evidence in support of the IPA findings but not as the main evidence.

The data analysis was done by following six steps of the IPA analytical procedure described by Smith et al. (2009). During Stage 1 each interview transcript was read and reread several times by the first researcher, a psychologist with experience in the field of disability caregiving, who completed initial exploratory notes in the left margin of the transcript, which included observations on the participant's language, emotional tone, how the narrative was structured, and any initial interpretive thoughts. In Stage 2, the first researcher re-read the transcript and outlined emergent themes in the right-hand margin, using his exploratory notes to provide concise conceptual labels that captured the psychological content and interpretive significance of meaningful segments of the participant's account. The two-stage reading and coding process provides the basis for the analytical process from experiential description to psychological interpretation, by first closely attending to each participant's words and meanings and then proceeding to more abstract conceptual labelling (Smith et al., 2009).

At Stage 3 the emergent themes for each transcript were listed and analyzed for connections, patterns, and clustering, and related themes clustered into superordinate themes that were considered to represent higher order psychological content. Each

individual analysis of the participant's account in Stage 4 was reviewed and refined for internal coherence of the thematic structure, the presence of adequate evidential support for each theme, and the maintenance of complexity and variation within the participant's account. To synthesize the individual analyses in Stage 5, the individual themes were compared, contrasted, and collapsed into a master thematic framework that presented the shared (and variable) aspects of the mothers' experiences of well-being across the entire sample of participants. The cross-case thematic synthesis was oriented by the six dimensions of Ryff's framework of well-being to ensure the study is both theoretically oriented and based on what participants' accounts emerge as content (Smith et al., 2009). All quotes were translated into English by the research team and a ten per cent random sample of twenty-five per cent was back translated to ensure that the translation was accurate and conveyed the participant's message. The thematic analysis procedure of Braun and Clarke (2006) was used to analyze the FGD transcripts, and then they were used to support the analysis at the theme level as additional triangulation evidence (Braun and Clarke, 2006).

4.4 Trustworthiness and Rigor

The trustworthiness of this qualitative study was determined through the use of the four criteria of rigorous qualitative inquiry as adapted to the methodological context of IPA proposed by Lincoln and Guba (1985). The credibility was reinforced through: prolonged engagement with each participant in individual interviews of substantial length; member checking, whereby interpretive summaries of individual experience were returned to a sub-set of eight participants for the purpose of checking the analytical accuracy of the interpretation, and the participants were given the opportunity to correct, expand, or challenge the researcher's interpretation; methodological triangulation of the individual IPA interview data with the data from the FGDs; and peer de-briefing sessions between the three researchers at fortnightly intervals during the analytical process, which enabled critical examination of interpretive decisions, and the identification of analytical blind spots. The first researcher's background as a psychologist with clinical experience in disability related mental health also added to the credibility of interpretations of psychological well-being constructs; and the second and third researchers professional background as special education practitioners (JSET in hearing impairment and visual impairment respectively) added to the contextual understanding of institutional and professional dimensions of participants accounts (Smith et al, 2009).

Thick description of the characteristics of the participants, the institutional and community context of the study and the sociocultural context of the disability caregiving in Punjab supported transferability by allowing the reader to evaluate the applicability of the results to comparable contexts of disability caregiving, in similar sociocultural settings. An extensive audit trail was kept, from exploratory notes to emergent themes and superordinate themes, to cross-case analysis and the final report, to ensure dependability by allowing external reviewers to follow the analytic process from raw data to reported findings. Systematic researcher reflexivity was conducted to address the issue of confirmability; each researcher kept a reflexivity journal to record their professional background, personal relationships to disability (where applicable), prior theoretical ideas about maternal well-being/caring, and how these positionalities changed over time and impacted their analysis of the data. During the analysis, the reflexivity journals were shared and discussed with the research team (Creswell, 2013).

5. Thematic Analysis Across Ryff's Dimensions

5.1 Self-Acceptance: Working through guilt, stigma, and rebuilding the maternal value.

One of the most consistently and significantly undermined dimensions of psychological well-being in the IPA analysis of the mothers' experience was the self-acceptance component of the Ryff model. This experiential structure was observed across all twenty individual participant analyses: an early phase of intense self-blame and self-guilt following the child's diagnosis due to the social attributions of disability to maternal failure; a prolonged phase of self-stigma, the internalization of socially devalued identity attributions, that led to a long-term impact on participants' sense of self-worth; and finally, for many but not all of the participants, a gradual and often challenging process of rebuilding self-acceptance through religious reframing, peer support, or acquisition of disability advocacy expertise (Corrigan, 2007). One participant, mother of a child with ASD from Multan, was extremely specific about the pain of the experience of self-blame: "When he was diagnosed, my first thought was what did I do wrong." My in-laws said it's from within my family. My husband didn't actually say that but it was in his eyes. For two years I believed it. I believed that I hurt my kid. Sixteen of the 20 participant analyses were reproduced, varying in the specific disability category and family dynamics, to tell the story of guilt driven self-blame and internalized self-stigma.

This phenomenological process of gradual reconstruction of self-acceptance was found to be neither linear nor complete in most of the participants, and to draw upon multiple experiential resources, as uncovered by IPA analysis. Fourteen participants described Islamic religious reframing, with the child with a disability interpreted as a blessing from God, and the role of the mother as a spiritually valued responsibility, as the most important contributor to maternal reconstruction of worth. Nine participants described peer support as transformative and validating because it was a connection with other mothers who experienced the same caregiving situation and did not blame or shame the caregiving situation. For some of the participants, reconstructed self-acceptance emerged as a result of the development of advocacy expertise — that the knowledge they developed of their child's rights and their commitment to their child's rights was a competence worthy of respect, because it was a disempowering experience in the special education system that formed their identity.

5.2 Interpersonal Relations: Alienation, marital difficulties, and the need for peer interaction

In the IPA analysis, the positive relations dimension was found to be disrupted for most of the mothers who participated in the study, and the mechanisms of disruption were found to be occurring concurrently: stigma-related social withdrawal, constraints in practical care-taking, and breakdown of marital and extended family relationships. Participants explained how they gradually started to avoid community activities and events to prevent their children's behavioural and developmental differences being exposed to the public and the community's judgment. One participant from Lahore spoke in a very metaphorical manner about the social shrinkage of the world he or she had known before the diagnosis of the daughter: 'Before the diagnosis of my daughter I had twenty friends. Now I have two. The others gradually went away. Some replied that they were occupied. Some said that their kids were afraid of my daughter. Others simply ceased telephoning. I knew, but I knew not that it was not so, But to know it not was to suffer more.

Marital relationships were identified as a relational area of particular vulnerability, wherein nine of the 20 participants expressed significant marital strains due to the disability caregiving relationship, including issues of child disability source, treatment and

educational decisions, financial strains of the disability situation, and relational distance from different coping styles. Most of the communities of the participants were culturally non-acceptable to separation, making it difficult for people to break up their marriages and adding a burden of relational tension to their caregiving obligations. In this context of relational disruptions, participants' access to peer support groups through informal networks linked to their children's government SECs was identified as the most psychologically restorative relational resource: it offered a sense of normalisation of emotional experience; information flows concerning practical matters such as food and housing; and the sense of not being alone in one's situation.

5.3 Autonomy: Selfhood Subsumed and the Loss of Personal Agency

Three participant analyses revealed that the autonomy dimension (which includes self-determination, personal freedom of choice, and assessing one's life through one's own values) was widely stymied by the combination of high demands on the mother as a caregiver, male-dominated families in decision-making, and the notion that mothers are supposed to sacrifice themselves for the benefit of the family. Participants described how the personal space (spatial, temporal, and psychological) that was narrowed as a result of intensive disability care-giving was created over the course of years of disability caregiving demands. A mother of a child with cerebral palsy from a district level institution said, 'I did not make a decision for myself for seven years'. Everything is scheduled around his eating, sleeping, going to bed and what not. I used to have ideas about my life. I don't remember now if I ever had that person within me. This description of the loss of the boundaries between the autonomous self and the mother/father-in-caregiving, the "disintegration of the self into the other," was reproduced in twelve analyses of participant's experiences in varying degrees of experiential acuteness, as both the objective restrictions of intensive caring and the cultural idealization of selfless motherly devotion work to create and maintain these restrictions ideologically.

5.4 Environmental Mastery: Helplessness to Advocacy Expertise

The environmental mastery dimension was the most dynamic experiential structure across the IPA analysis, ranging from helplessness in early caregiving, to gradual competence-building, to in some instances, expert advocacy skills. On the part of the mothers, the first few years of disability identification and access to services were consistently described as a time of extreme environmental helplessness: lack of familiarization in the diagnostic and educational systems, professional gatekeeping, financial constraints, and a lack of peer support left the newly identified mothers feeling overwhelmed, invisible, and incompetent in the presence of the institutional complexity. However, as the time went on, most of the participants referred to a gradual acquisition over time of 'fighting spirit,' 'knowing my rights,' and 'learning the system,' all of which could be called disability-related expertise, as described in the qualitative disability literature (Hastings & Taunt, 2002). One mother with eleven years' experience in child care in Multan expressed her pride in this path vividly: 'I used to weep at every door of the offices. Now they know me. I know whom to go to, which forms to fill, which officer to turn to. I learned on my own because no one taught me. But I know something which I was not able to know I would know! This class discusses the Islamic meanings of life and the advocacy calling, and how those two are interconnected.

Characteristic phenomenological structure emerged across the participant analyses in the purpose in life dimension: the initial phase was characterized by a great disruption in purpose after the diagnosis, when the developmental plans for the typically developing child and its implications for the mother's sense of the purpose of her parenting and its

direction were suddenly unsettled; a second phase, during which purpose was gradually reconstructed, was driven by two major meaning-making resources: the mother's need to make sense of the situation and her need to act. The first and most universally described resource was Islamic spiritual meaning-making, reframing of the child's disability within an Islamic theological narrative of divine test, divinely given gift, and divinely-rewarded patient endurance, which in turn oriented and informed the meaning of the caregiving situation from the cosmic perspective despite its experiential demands. Out of twenty participants, seventeen identified their Islamic faith as the most important source of purposefulness that sustains their investment in caring over the years of institutional challenge and meager visible outcomes (Miles, 2002).

The second resource for meaning was the advocacy purpose—inspiring a mission-driven passion for advocating for the child's rights, for improving services for all children with disabilities, and for confronting stigma and institutional indifference, which had been a feature of participants' own institutional experiences. For some participants, the advocacy reason was no longer being for their own child, but instead involved being involved in parent associations, community raising awareness initiatives and responding to government officials, making their caregiving experience more socially relevant and consequential than simply advocating for a single child. One of the participants from Lahore commented, 'I used to fight just for my son. 'Now I fight for all the children like him. That is my purpose. That's why I have come here.

5.5 Personal Growth: Transformative Gains and Profound Loss

The findings of the IPA analysis were very complex and rich in the personal growth dimension, in which personal growth, in the form of increased empathy, values, advocacy capacity, and views of human worth, were experienced alongside, and not in lieu of, the grief, fatigue, and loss experienced during the care of disability. The phenomenon of growth and loss in the same psychological experience is the hallmark of what is called posttraumatic growth (PTG) in the qualitative disability literature (Bayat, 2007), and its presence across the participant sample represents one of the most important findings of this study for implications for psychological theory and interventions.

Participants talked about a range of specific dimensions of personal growth: they spoke of a greater sense of vulnerability and suffering that went beyond their own situation in the family to a broader sense of compassionate engagement with others facing hardships; a shift in the hierarchy of values from one that is more focused on social achievement, material success and conventional normality to one that prioritizes human connection, dignity and acceptance; a deepened capacity for patience: years of incremental developmental progress, celebrated without the pressure of the milestones that parenting a typically developing child would take for granted; and an advocacy competence and moral courage that was consistently described as emerging from the experience of institutional discrimination and social stigma directed at their children. One mother said, 'I'm a better woman than I was before he was diagnosed. I know that sounds wrong, he's suffered and I've suffered. I am more patient, kinder than I was before, more certain of what's important. I would never return to myself, if I could I would change his condition.'

6. Discussion

Overall, the IPA findings, which are analysed within the framework provided by Ryff's Multidimensional Model of Psychological Well-Being, offer an understanding of how maternal well-being was experienced rather than the stress and distress perspective that is offered in the existing literature from Pakistan. Ryff's model captures the negative experiences and positive outcomes of the psychological well-being in six dimensions, thus

offering a framework for more fully describing the Punjabi maternal experience than a one-dimensional stress or burden approach and more useful for designing interventions.
The most theoretically important result of the IPA analysis using the Ryff guide is the presence of substantial well-being deficits as well as strong well-being indicators in the same experiences for each mother. For mothers with strong disruption of their self-acceptance and autonomy components, their life purpose and personal growth are extraordinary. The social isolation that leads to a devastated positive relations dimension in mothers is connected to the creation of deep and meaningful relationships with their children that can be viewed as a relational well-being resource. Mothers whose mastery of the environment is continually undermined through lack of accessibility build up a level of advocacy expertise that is quite sophisticated. A unidimensional measure of well-being or an analytical approach that focuses solely on deficits cannot adequately depict this co-presence of deficit and strength in the same psychological experiences, which is precisely what the model of positive psychology (Ryff & Singer, 2008) does.
The IPA methodology is both hermeneutic, meaning it seeks to elicit participant meaning in the process and her interpretive meaning in the process, and produced analytical insights which would not have been possible within a purely descriptive thematic approach. One of the most clinically and programmatic important findings of the study was the developmental phenomenological trajectory identified within the environmental mastery dimension: initial helplessness, progressive competence, and advocacy expertise, as seen in participants' accounts of the narrative structure, metaphoric expression, and tensions and contradictions within accounts. This is not only a way of dealing with the negative circumstances, but rather a type of expertise that is professionally significant and that can be developed and engaged with in the system to enhance the system (Scorgie & Sobsey, 2000).
In this study, Islamic spiritual frameworks have a significant implication in culturally responsive intervention design as the most universally described source of purpose reconstruction and self-acceptance recovery. Some interventions involving the use of Islamic theological ideas, related to disability, patience and spiritual meaning of caring were more culturally accessible and psychologically resonant for Punjabi mothers than secular psychological interventions, where the religious meaning-making frameworks were not recognized in caring situations (Miles, 2002).

7. Findings

This qualitative IPA study has a number of methodological limitations that need to be explicit stated. Second, the sample was purposively selected from government special education centers in three districts of Punjab; thus, the findings may not reflect the actual experiences of material circumstances, institutional experiences, and psychological well-being of mothers whose children attend private special education institutions, mainstream schools with resource room, or do not receive any special education program, as their circumstances may vary significantly from that of the government SEC-attending population that has been studied. Secondly, the characteristic feature of the IPA methodology, which is the use of depth of idiographic analysis, by design, limits the ability of findings to be statistically generalized to the larger population of Punjabi mothers of children with developmental disabilities. The results should be interpreted as theoretically generalizable (applicable to similar contexts of caregiving) but not statistically generalizable to a given population. Third, it has only been mothers who were the participants in the study, which is characteristic of the study population but also means the experience of paternal well-being was completely missing from the results. Moving

forward, further research should incorporate fathers as a unique participant group because the psychological health consequences of secondary caregiving roles, and social norms regarding stoic fatherhood responses to disability could produce unique and clinically meaningful structures of phenomena to be systematically examined. Fourth, the researchers' professional backgrounds, including the first researcher's clinical psychology background, and the second and third researchers' backgrounds as Special Education practitioners, added to the credibility to some interpretation of the analysis, may also have introduced professional orientations that influenced which elements of the experiential aspects received the most emphasis in the analysis. This potential influence was mitigated to some extent but not fully removed using reflexivity journals and peer de-briefing.

8. Recommendations

The Government of Punjab's Directorate of Special Education should ensure that a network of Caregiver Psychological Support Services is established in the government special education centers throughout Punjab and the clinical/counselling psychologists employed should have a particular competency in the field of disability-related grief, caregiver burnout, and positive psychology intervention. They should provide individual counselling for mothers with clinical levels of depression, anxiety or grief, evidence-based psycho-education on coping, self-care and psychological literacy in relation to mothers' well-being, and facilitated peer support groups for connection, normalisation and empowerment as identified in the literature as one of the most psychologically restorative supports for mothers in caring roles (Emerson & Hatton, 2014). Their embedding in special education centers, instead of in separate mental health institutions, eliminates barriers and stigma to mental health service seeking, and builds on existing institutional connections that mothers already have with the special education system.

A provincial Respite Care Program for families of children with developmental disabilities should be established that includes after-school/over weekend respite sessions within government special education center premises, trained home-visitor respite services for families living in the rural and peri-urban areas and emergency respite provisions for families having a care-giving crisis. The universities that run clinical psychology and social work degree programs in Punjab should incorporate a specialized course in disability caregiving into the curriculum for graduate clinical training programs, and make it culturally responsive for the graduates to be able to offer psychological support to the mothers of children with developmental disabilities. Psychoeducational materials on emotional self-care, Islamic perspectives on disability and caregiving, stigma management strategies, and guidance for navigating services should be developed in Urdu, and shared through government special education centers and networks of Lady Health Workers (LHWs) (Singer, 2006).

The Government of Punjab should create a Disability Family Support Policy that takes the psychological health of primary maternal caregivers as a valid and priority concern of the special education system; and allocate a specific budget for caregiver support services, respite care programs, and integration of maternal mental health into the special education service delivery system. This policy recognition would mark a paradigm shift in the way the special education system views its responsibility, from primarily working with the child with a disability to working with the family, recognizing the child's developmental/psychological outcomes as being part and parcel of the primary caregiver's psychological health and functioning. There is strong international evidence that supports this systemic expansion, including the fact that investing in maternal psychological well-

being is among the highest return interventions that can be done to improve developmental outcomes of children in disability caregiving contexts (Bayat, 2007).

9. Conclusion

This qualitative IPA study has emerged a theoretically rich, methodologically sound and experientially genuine description of mothers' psychological well being in the context of developmental disabilities in Punjab. In an interpretivist paradigm, using twenty individual in-depth interviews and three focused group discussions and the six-dimensional framework of the Ryff Multidimensional Model of Psychological Well-Being, the study has uncovered a landscape of maternal experience characterized both by profound psychological challenges in the self-acceptance, positive relations and autonomy dimensions, and by remarkable psychological strength in the purpose in life and personal growth dimensions — a co-presence of deficit and strength that is theoretically productive, clinically important and practically consequential for intervention design.

Punjab's social service provision system has been one of the most psychologically resilient and the most under-served populations in this study, being the Punjabi mothers. The strength of their survival does not diminish the need for support – it is proof of the enormous resilience of the human species in circumstances that are not supposed to be endured without the help of professionals, their social networks or the state. The recommendations in Section 8 are the result of an evidence-based and culturally responsive roadmap for providing that assistance: psychologist staffed caregiver support services; provincial respite care infrastructure; culturally adapted psychoeducational resources; reforming graduate clinical training; and a formal Disability Family Support Policy, which ensures that maternal well-being is understood, valued, and treated as a priority within the system rather than an afterthought.

Longitudinal studies of maternal well-being throughout the child's developmental lifespan, instrument validation studies to create culturally appropriate, Urdu-language assessments of maternal well-being based on the multidimensionality of the Ryff and intervention evaluation studies to rigorously evaluate the effectiveness of culturally adapted peer support groups, Islamic-framework-informed psychoeducational programs, and respite care provisions in the maternal psychological well-being outcomes in the disability-based care taking context of Punjab should be investigated in the future. The investment in this research agenda is an investment in scientific knowledge and also in the lived psychological flourishing of the mothers whose caregiving love and advocacy commitment is most powerful, and least supported, aspect of the special education system in Punjab.

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