

Parents' Psychological Adaptation after Receiving a Fetal Diagnosis: A Systematic Review

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A fetal diagnosis places an unexpected psychological burden on parents and triggers a complex pregnancy experience. Parents who choose to continue the pregnancy have unique perspectives as they prepare for birth. It is crucial to understand these families' experiences to inform their care and support. This qualitative systematic review explored the psychological adjustment of parents who continued gestation after they received a fetal diagnosis. A systematic database search was conducted with subsequent thematic analysis of fourteen included studies. Parents experienced intense initial emotional reactions to the diagnosis including shock and grief, followed by a complex processing period influenced by personal and social factors. The findings demonstrate a need for improved multidisciplinary parental support for families who receive a fetal diagnosis and add rationale for the addition of psychological services to the care teams of prospective parents.
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Pregnancy is a time of major life adjustment for any parent. Parents who undergo typical pregnancies experience changes in lifestyles, emotions, and identities (Edvardsson et al., 2011). Pregnancies that receive a fetal diagnosis place an additional psychological burden on prospective parents, especially at the time of initial identification (van der Steen et al., 2016). These stressors continue after birth as the family shifts into living daily life with the infant and their specific developmental needs (Woolf-King et al., 2017).

Due to advances in technologies, such as non-invasive methods, prenatal screenings have become standard in much of the developed world (Pös et al., 2019; WHO, 2012). These screenings are generally accepted and perceived as necessary by parents (Aune & Möller, 2010, Ekelin et al., 2016), and receiving positive, on-track information about their unborn child's development can contribute to a positive pregnancy experience (Richter et al., 2020; Wittman et al., 2016). However, the widespread use of modern screening technologies also means greater detection of prenatal conditions such as birth defects or genetic disorders (Carlson & Vora, 2017). Reports show that about one in 33 births is complicated by a birth defect (CDC, 2008) which can often result in physical or mental disabilities (Boyle & Cordero, 2005).

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nancy experience (Richter et al., 2020; Wittman et al., 2016). However, the widespread use of modern screening technologies also means greater detection of prenatal conditions such as birth defects or genetic disorders (Carlson & Vora, 2017). Reports show that about one in 33 births is complicated by a birth defect (CDC, 2008) which can often result in physical or mental disabilities (Boyle & Cordero, 2005).

A fetal diagnosis is difficult news for families to receive. While many families decide to terminate these pregnancies (Hawkins et al., 2012), some families decide to continue. In recent years, rates of continued pregnancy after receiving a fetal diagnosis have increased (Madeuf et al., 2016). The decision to continue a pregnancy is multifaceted. For many parents it is an ethical dilemma, with worries over playing God and wanting the pregnancy to occur naturally, or they feel a sentimental attachment to the fetus (Winn et al., 2018). The timing of diagnosis also matters. Parents farther along in gestation have a greater likelihood of choosing to continue the pregnancy (Madeuf et al., 2016; Michalik & Preis, 2013; Winn et al., 2018). Additionally, diagnosis severity and other variables play a role, where less severe fetal diagnoses and conditions with a history of greater postnatal success have a higher likelihood of pregnancy continuation (Hawkins et al., 2012; Madeuf et al., 2016; Winn et al., 2018). Other socio-contextual factors such as parental education, race, geographic location, and finances also impact the decision (Hawkins et al., 2012; Michalik & Preis, 2013).

For parents, the decision to continue pregnancy rather than terminate may improve their psychological outcomes (Cope et al., 2015), a crucial buffer as prospective parents already face vulnerabilities to their

mental health during pregnancy (Cindy-Lee et al., 2017; Condon et al., 2004; Davalos et al., 2012). In typical pregnancies, factors such as lower socioeconomic status, financial hardships, younger maternal age, and histories of prior mental health struggles, put women at an increased risk for mental health conditions such as depression (Rich-Edwards et al., 2006). Lower social support is also a risk factor; parents with low social support may lack social networks which can provide advice, information, and reduce negative emotions that may result from stressors (Bedaso et al., 2021).

However, many factors can act protectively for prospective parents' psychological health, such as high social support which may promote psychological well-being (Corno et al., 2022). A qualitative study on public health clinics found that pregnant mothers utilized friendships to manage stress and relieve tension through venting and laughing together (Abdou et al., 2010). Similarly, relationship quality and partner support act as protective factors. Involved partners and strong relationships have been found to benefit maternal well-being for mothers undergoing typical pregnancies (Rini & Dunkel Schetter, 2010). Other literature on typical pregnancies has demonstrated that social support, family functioning, and relationship satisfaction buffered links between stressful events and depression (Divney et al., 2012). In recent work on specific stressful life events, such as the COVID-19 pandemic, support from partners, social networks, and healthcare providers was identified as playing protective roles in the mental health of pregnant women (Khoury et al., 2021; Vacaru et al., 2021). Further support can stem from parents' mindsets. Pregnant women who engaged in emotion-focused coping in early and middle pregnancy had lower distress (Huizink et al., 2002), and those with more positive cognitive appraisal in stressful life events like COVID-19 had less mental health problems (Khoury et al., 2021). Utilization of belief systems like religion or spirituality as a source of guidance or comfort has also been suggested as helpful factors (Abdou et al., 2010).

Further support of mental health vulnerabilities in pregnancy may be the receipt of psychological services (Kinser et al., 2021; Urizar et al., 2019), yet currently, many prospective parents undergoing typical pregnancies struggle to access adequate psychological services (Schwartz et al., 2021). Pilot intervention programs have been implemented to facilitate access

to services (Slade et al., 2021), yet less is known about universal or broader efforts. Supporting the spread of information, the internet has helped aid parents to access informational resources (Fleming et al., 2014). Recent years have seen the development and utilization of e-mental health tools, where parents use web-based strategies for the delivery or enhancement of mental health information and services (Fonseca et al., 2016). For high-risk pregnancies, including those with fetal diagnoses, formal social supports (e.g., targeted support networks within peers or practitioner-facilitated groups) are also documented as effective resources (Coffman & Ray, 2002; Kugler & Farmer, 2015).

It is important to note that culture is an important factor when considering the emotional well-being, coping, and resources of parents (Cindy-Lee et al., 2017; Dunkel Schetter, 2011). The availability of resources and reasons for seeking support varies across cultures and geographic regions (Baron et al., 2015; Dunkel Schetter, 2011; Tol et al., 2018), yet further knowledge is needed on parent emotional processing and use of supports across cultures. Similarly, much of the work on the emotional well-being, emotional processing, and subsequent resources for prospective parents has been performed with typical pregnancies, however, less is known on these topics for those with high-risk pregnancies such as fetal diagnoses. These parents may have unique needs and experiences (van der Steen et al., 2016), thus further exploration of their emotional process and the factors which influence this process is needed.

A prenatal diagnosis vastly shifts parents' perspectives of pregnancy (Horsch et al., 2013). Other reviews have explored this phenomenon, but none have focused solely on the emotional processing and acclimation of parents who decided to continue their pregnancy. Lou and colleagues (2017) completed a thorough review of parent responses to prenatal diagnosis that included studies with both continued and terminated pregnancies. Johnson and colleagues (2020) performed a comprehensive review of prospective parents' views when a fetal abnormality was identified but focused solely on anomalies detected via ultrasound and included insights from healthcare professionals.

Prior reviews offer important insights on parents and prenatal diagnosis, but additional work is needed on the psychological state and external influences for parents who continue these pregnancies to

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better understand parents of infants with atypical development. As such, the present systematic review aimed to synthesize the prenatal emotional adjustment of parents who continued pregnancy after receiving a fetal diagnosis and to identify factors influencing their emotional responses to the diagnosis.

Methods

Search Procedures

This review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. The search strategy utilized SPIDER, a search tool for qualitative research (Cooke et al., 2012). SPIDER identifies the (S) sample studied (“parents, prospective parents”), (PI) phenomenon of interest (“prenatal diagnosis, prospective pregnancy”), (D) targeted study design (“interview, survey”), (E) evaluation of the phenomenon (“experiences, perceptions”), and (R) type of research (“qualitative”).

Inclusion Criteria

Included studies were peer-reviewed original empirical works from any country that focused on the experiences of current or prospective parents (e.g., mother, father, familial caregivers) who continued their pregnancy after receiving a fetal diagnosis. Included studies focused on the prenatal period during and after the diagnosis, but prior to birth. If studies included both pre- and post-natal diagnoses, only prenatal data was used. Fetal diagnosis was conceptualized as an abnormality which would impact the child’s post-birth functioning, development, or health. Parents were conceptualized as any primary caregiver of the child in the perinatal period. Studies needed to utilize parent-reported qualitative data (e.g., solely qualitative articles or qualitative sections of articles using mixed methods) and be written in English.

Exclusion Criteria

Studies were excluded if they used solely quantitative methods or were not published in a peer-reviewed journal. Studies with quantitative data were excluded from the present review as the focus was to provide an in-depth synthesis of parent experiences and emotions, a level of depth often better captured by qualitative data as it highlights lived experiences of participants while quantitative approaches aim to quantify and or-

der participant data (Ponterotto, 2002). Studies with samples that included only stakeholders and no primary caregivers were excluded. Studies that included parent perspectives of terminated or miscarried pregnancies, or postnatally administered diagnoses, were also excluded. Studies were excluded that only focused on parents’ postnatal experiences, or only detailed parents’ prenatal experiences prior to an official diagnosis.

Study Selection

Study selection is summarized in Table 1. The selection process consisted of two stages. First, databases were searched using search terms and screened based on titles and abstracts. Next, full texts of eligible studies were read and eligibility criteria were applied, resulting in the inclusion of ten publications. A manual search of reference lists and library resources identified four more eligible papers, resulting in the inclusion of 14 total publications.

Quality Appraisal

Methodological quality of included studies was assessed by the author using the Critical Appraisal Skills Programme (CASP) qualitative appraisal tool (Critical Appraisal Skills Programme, 2018). The CASP tool evaluates based on criteria from three sections consisting of a total of ten items: A) Are the results of the study valid? (e.g., items 1) Was there a clear statement of the aims of the research? 2) Is a qualitative methodology appropriate? 3) Was the research design appropriate to address the aims of the research? 4) Was the recruitment strategy appropriate to the aims of the research? 5) Was the data collected in a way that addressed the research issue? 6) Has the relationship between the researcher and participants been adequately considered?, B) What are the results? (e.g., items 7) Have ethical issues been taken into consideration? 8) Was the data analysis sufficiently rigorous? 9) Is there a clear statement of findings?, and C) Will the results help locally? (e.g., item 10) How valuable is the research?). Each item was rated Yes, Can’t Tell, or No. After rating, each item was assigned a point value (i.e., Yes = 2, Can’t Tell = 1, No = 0) and items were totaled with 20 as the maximum possible score. Studies receiving a score of 17 or higher were classified as high methodological quality, scores between 16 and 14 as moderate methodological quality, and 13 or below as lesser methodological quality. No stud

ies were excluded because of the appraisal (Table 1).

Data Synthesis

This review utilized thematic analysis (Thomas & Harden, 2008) which allowed results of the included publications to be synthesized. Specifically, the analysis procedures employed a thematic synthesis approach outlined by Thomas and Harden (2008) which allows for an effective translation of concepts and connection of qualitative research findings. The thematic synthesis guidelines were used to generate and identify themes and subthemes. First, included studies were read multiple times and notes were taken of initial ideas for coding. Next, the qualitative results sections of each study were reviewed and coded into a set of initial, broad codes. Data relevant to each code was extracted and sorted under the respective code. Codes were inductively developed and added to as needed, resulting in a set of overarching themes (e.g., initial reactions, processing period, social factors, and coping strategies) which were checked for fit with the data then defined and named. From here, data under each theme was reviewed and sorted further into narrower subthemes under each broader theme. Subthemes were reviewed and refined for fit within the broader themes.

Results

The 14 included studies were conducted in a range of countries: five from the United States, three from Australia, two from Sweden, one from Denmark, one from Ireland, one from South Korea, and one from the United Kingdom. The studies included a total of 251 primary caregivers, including 173 mothers, 67 fathers, nine grandparents, and two undisclosed sexes. While included studies varied in aims, qualitative design, and distinct focus, all examined parents' insight and experiences after receiving a prenatal diagnosis.

Based on the thematic analysis (Thomas & Harden, 2008), the synthesized results show that emotional adjustment to a fetal diagnosis was an ongoing process characterized by two main timepoints: initial diagnosis and processing period. Table 2 details a summary of themes and corresponding studies. Parents experienced different perspectives depending on the timepoint. They reported early emotions at the time of diagnosis, then shifted emotions as they underwent the processing period. While families consistently reacted strongly to the initial diagnosis, these emotions

were not homogenous and shifted as parents adjusted to the news. Individual parent experiences of the overall adjustment process were influenced by two main factors: interactions with others and coping strategies. Figure 2 models parents' emotional process.

Initial Reactions. Parents reported a range of emotions when they first received the fetal diagnosis. Most parents described intense shock when they received the news (Carlsson et al., 2017; Clark et al., 2020; Côté-Arsenault & Denney-Koelsch, 2011; Goff et al., 2013; Hickerton et al., 2011; How et al., 2019; Im et al., 2018; Johnson et al., 2018; Lokmic et al., 2017; McKechnie & Pridham, 2012; O'Connell et al., 2019) and described how this shock made it difficult to grasp the diagnosis (Carlsson et al., 2017). Shock was especially salient in first-time mothers (O'Connell et al., 2019). Parents also reported grief, sadness, and mourning (Carlsson et al., 2015; Carlsson et al., 2017; Clark et al., 2020; Côté-Arsenault & Denney-Koelsch, 2011; Hickerton et al., 2011; How et al., 2019; Im et al., 2018; Johnson et al., 2018; Lou et al., 2020; McKechnie & Pridham, 2012; McKechnie et al., 2015; O'Connell et al., 2019). They described intense emotional suffering and devastation (Carlsson et al., 2015; Clark et al., 2020; Im et al., 2018; McKechnie & Pridham, 2012; O'Connell et al., 2019), and felt a deep sense of loss surrounding their original expectations for the child and pregnancy (Côté-Arsenault & Denney-Koelsch, 2011; Hickerton et al., 2011; Johnson et al., 2018; Lou et al., 2020; McKechnie et al., 2015).

A portion of parents felt anger when they first heard the diagnosis (Carlsson et al., 2017; Goff et al., 2013) while others felt confused (Carlsson et al., 2015; Hickerton et al., 2011; Im et al., 2018; McKechnie & Pridham, 2015). They questioned why (Goff et al., 2013; McKechnie & Pridham, 2012) and felt the diagnosis did not make sense (Carlsson et al., 2015; Im et al., 2018). Many parents also reported fear and anxiety (Carlsson et al., 2015; Im et al., 2018; Johnson et al., 2018; Lokmic et al., 2017; Lou et al., 2020; McKechnie et al., 2015). Some were fearful of fetal loss or worsening of the condition (Carlsson et al., 2015; McKechnie et al., 2015), while others experienced panic about the future (Im et al., 2018; Lou et al., 2020). Parents also reported feelings of guilt (Carlsson et al., 2017; Clark et al., 2020; Côté-Arsenault & Denney-Koelsch, 2011; Hickerton et al., 2011; Im et al., 2018; Lokmic et al., 2017). Many felt guilt for potentially causing the

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anomaly (Carlsson et al., 2017; Côté-Arsenault & Denney-Koelsch, 2011; Lokmic et al., 2017), while others felt moral guilt in considering whether to terminate the pregnancy (Im et al., 2018; Hickerton et al., 2011). For some parents, guilt was compounded with other emotions, like guilt about their sadness or hope for a false-positive diagnosis (Carlsson et al., 2017; Clark et al., 2020; Côté-Arsenault & Denney-Koelsch, 2011).

Overall Trends during the Processing Period.

Adjusting to the diagnosis was a process for parents. They overwhelmingly reported gratitude in receiving the diagnosis prenatally versus postnatally (Carlsson et al., 2015; Carlsson et al., 2017; Clark et al., 2020; Côté-Arsenault & Denney-Koelsch, 2011; Goff et al., 2013; Hickerton et al., 2011; How et al., 2019; Im et al., 2018; Johnson et al., 2018; Lokmic et al., 2017; Lou et al., 2020; McKechnie & Pridham, 2012; McKechnie et al., 2015; O'Connell et al., 2019) as this gave them time to prepare. However, after receiving the diagnosis, parents felt they needed time to digest the news (Clark et al., 2020; Goff et al., 2013; How et al., 2019; McKechnie & Pridham, 2012). In this processing period, they shifted their thoughts and feelings toward the future (Carlsson et al., 2015; Carlsson et al., 2017; Clark et al., 2020; Goff et al., 2013; Hickerton et al., 2011; How et al., 2019; Im et al., 2018; Johnson et al., 2018; Lou et al., 2020; McKechnie & Pridham, 2012; McKechnie et al., 2015). As they looked ahead, most described an acceptance of the diagnosis (Carlsson et al., 2015; Carlsson et al., 2017; Clark et al., 2020; Goff et al., 2013; Hickerton et al., 2011; How et al., 2019; Im et al., 2018; Lou et al., 2020; McKechnie & Pridham, 2012; McKechnie et al., 2015). Many felt having time to process emotions helped their acceptance (Clark et al., 2020; How et al., 2019; Goff et al., 2013; McKechnie & Pridham, 2012), and used this time to reframe their original expectations of the child, future parenting, and life milestones (Hickerton et al., 2011; McKechnie et al., 2015). Parents began to celebrate and see their unborn baby as any other child, with individuality, personality, and hardships that all parents face (Goff et al., 2013; How et al., 2019; Im et al., 2018; Lou et al., 2020; McKechnie et al., 2015).

Despite acceptance of their future child and circumstances, most parents reported ongoing anxieties during the processing period (Carlsson et al., 2015; Carlsson et al., 2017; Clark et al., 2020; Goff et al., 2013; Hickerton et al., 2011; How et al., 2019; Im et

al., 2018; Johnson et al., 2018; Lou et al., 2020; McKechnie & Pridham, 2012; McKechnie et al., 2015; O'Connell et al., 2019). Worries focused on the current pregnancy and the remaining gestational development of their child (Carlsson et al., 2017; How et al., 2019; Lou et al., 2020; McKechnie & Pridham, 2012; McKechnie et al., 2015). Other fears revolved around the future. Parents were uncertain about the outlook for themselves and their child (Carlsson et al., 2015; Carlsson et al., 2017; Clark et al., 2020; Goff et al., 2013; Hickerton et al., 2011; 2013; Johnson et al., 2018; Lou et al., 2020; McKechnie & Pridham, 2012; McKechnie et al., 2015). They worried about navigating the new influx of information and meeting their child's future needs, such as medical and other support services (Carlsson et al., 2017; Clark et al., 2020; McKechnie & Pridham, 2012; McKechnie et al., 2015). Many felt societal pressures such as the expectation to produce a healthy child (Im et al., 2018), the impact of a child with a disability on family functioning (Carlsson et al., 2015; Carlsson et al., 2017; Goff et al., 2013; Lou et al., 2020), and their child's future social experiences including stigma and social milestones (Clark et al., 2020; Johnson et al., 2018; Lou et al., 2020; McKechnie et al., 2015). Parents also reported uncertainty in their social functioning, especially when interacting with parents of typically developed children (Goff et al., 2013; Hickerton et al., 2011; Johnson et al., 2018).

Though anxious, parents reported a newfound bond with their unborn child (Carlsson et al., 2017; Côté-Arsenault & Denney-Koelsch, 2011; Im et al., 2018; Lou et al., 2020; McKechnie et al., 2015; O'Connell et al., 2019). As they accepted their child, they described a strong sense of love and attachment and felt an increasing connection that strengthened their parental duty and commitment (Carlsson et al., 2017; Im et al., 2018; Lou et al., 2020; McKechnie et al., 2015; O'Connell et al., 2019). They saw their baby as an individual, and desired for others to view their child the same way (Côté-Arsenault & Denney-Koelsch, 2011; How et al., 2019; Im et al., 2018; O'Connell et al., 2018). Filled with acceptance and love, parents reported feelings of positivity and hope as they progressed through the pregnancy (Clark et al., 2020; Im et al., 2018; McKechnie & Pridham, 2012; McKechnie et al., 2015).

Influencing factors. Despite consistent overall trends, parents did not all follow the same rate of adjustment during the processing period. Some had

a slower adjustment and others rebounded from the diagnosis quickly. Some had a positive, fulfilling pregnancy, while others felt more cynical and distanced. Emergent themes evidenced that experiences were shaped by outside factors. Throughout included studies, parents mentioned multifaceted details in social interactions and coping strategies which contributed to their pregnancy experience and acclimation process.

Social Interactions with Others

Medical Professionals. Medical professionals ranged from doctors, nurses, doulas, and other pregnancy support staff. Some parents developed close relationships with their healthcare professionals and communicated with them frequently after receiving the diagnosis (McKechnie & Pridham, 2012; McKechnie et al., 2015). These parents had a select few which they trusted and looked to for support (Carlsson et al., 2015; Goff et al., 2013; Hickerton et al., 2011; Lou et al., 2020). They appreciated their knowledge and advice relating to the pregnancy and diagnosis (Carlsson et al., 2015; Côté-Arsenault & Denney-Koelsch, 2011; Hickerton et al., 2011; How et al., 2019; Im et al., 2018; McKechnie et al., 2015; O'Connell et al., 2019). Parents were especially satisfied when medical professionals listened and supported their decisions and felt most at ease getting continuous care from their trusted team (Carlsson et al., 2015; Hickerton et al., Lou et al., 2020).

However, many parents in included studies overwhelmingly reported negative experiences with medical professionals after the diagnosis. They reported that healthcare professionals had pessimistic attitudes and delivered diagnostic news poorly (Carlsson et al., 2015; Clark et al., 2020; Côté-Arsenault & Denney-Koelsch, 2011; Goff et al., 2013; Hickerton et al., 2011; Im et al., 2018; Johnson et al., 2018; Lokmic et al., 2017; Lou et al., 2020; McKechnie et al., 2015; O'Connell et al., 2019). Parents felt providers held negative stereotypes about disabilities and routinely pushed for a termination of pregnancy, often making repeated comments about termination (Goff et al., 2013; Hickerton et al., 2011; How et al., 2018; Johnson et al., 2018; Lokmic et al., 2017; Lou et al., 2020). Many parents described medical professionals as grim, unemotional, and uncompassionate in their care (Clark et al., 2020; Goff et al., 2013; Lou et al., 2020), and recounted hurtful, inappropriate remarks from providers about their babies and choices (John-

son et al., 2018; McKechnie et al., 2015; O'Connell et al., 2019). Parents felt the professionals lacked crucial knowledge and resources about the diagnoses and were inconsistent in the advice and information they shared (Carlsson et al., 2015; Carlsson et al., 2017; Côté-Arsenault & Denney-Koelsch, 2011; Goff et al., 2013; Johnson et al., 2018; Lokmic et al., 2017; Lou et al., 2020). Often, unannounced specialists attended appointments, which made parents increasingly anxious and distrustful (Johnson et al., 2018; Lokmic et al., 2017).

Friends and Family. Family and friends ranged from immediate and extended family to circles of friends. Parents' social networks were important sources of support during the pregnancy (Carlsson et al., 2017; Clark et al., 2020; Côté-Arsenault & Denney-Koelsch, 2011; Goff et al., 2013; Hickerton et al., 2011; McKechnie & Pridham, 2012; McKechnie et al., 2015; O'Connell et al., 2019). Parents retreated to their trusted, inner social circles after the diagnosis (Clark et al., 2020; McKechnie & Pridham, 2012; O'Connell et al., 2019), and relied on them to listen and help with practical needs (Carlsson et al., 2017; McKechnie & Pridham, 2012).

However, not all of the parents' social groups were accepting or helpful (Carlsson et al., 2017; Clark et al., 2020; Côté-Arsenault & Denney-Koelsch, 2011; Hickerton et al., 2011; How et al., 2019; McKechnie et al., 2015; O'Connell et al., 2019). Parents felt family and friends were not always supportive (Côté-Arsenault & Denney-Koelsch, 2011; Hickerton et al., 2011; McKechnie et al., 2015). Parents received insensitive remarks and felt pressured by others to terminate the pregnancy (Hickerton et al., 2011; How et al., 2019; O'Connell et al., 2019). Many friends and family members were unsure how to respond to the diagnosis, while others refused to accept the pregnancy or unborn baby (Clark et al., 2020; Côté-Arsenault & Denney-Koelsch, 2011; Hickerton et al., 2011). Parents felt lonely, isolated, and stigmatized, and felt others could no longer relate to them (Côté-Arsenault & Denney-Koelsch, 2011; McKechnie et al., 2015, O'Connell et al., 2019). They underwent a great divide in their personal and social experiences and reported the distancing and changing of friendships (Carlsson et al., 2017; Côté-Arsenault & Denney-Koelsch, 2011; McKechnie et al., 2015).

Parents' Coping Strategies

Research and Information-Gathering. Most parents felt a need to find information on the diagnosis, which they did through personal research. They tried to educate themselves and build their knowledge as much as possible so they could be prepared for the future (Carlsson et al., 2015; Carlsson et al., 2017; Clark et al., 2020; Im et al., 2018; Johnson et al., 2018; Lokmic et al., 2017; Lou et al., 2020; McKechnie & Pridham, 2012; McKechnie et al., 2015; O'Connell et al., 2019). Some found this strategy helpful and attained valuable information on their baby's condition (Carlsson et al., 2015; Im et al., 2018; Lou et al., 2020; McKechnie & Pridham, 2012), while others found it overwhelming and confusing due to the large quantity of resources, much of it negative or outdated (Carlsson et al., 2015; Clark et al., 2020; Lokmic et al., 2017; McKechnie & Pridham, 2012; McKechnie et al., 2015).

Experiential Knowledge. Parents also relied on the experiences of other families with the same diagnoses. Some parents connected with these families through their research efforts, while others reached out to families they already knew. For some, the experiences of others caused fear and distress, especially in cases with poor outcomes (Carlsson et al., 2015; Carlsson et al., 2017; McKechnie et al., 2015). But for many, the experiences of other parents helped them feel positive and reassured (Clark et al., 2020; Johnson et al., 2018; Lokmic et al., 2017; McKechnie & Pridham, 2012; McKechnie et al., 2015; O'Connell et al., 2019). Collaborating with others lessened their anxiety and reshaped expectations, especially when they saw children with similar conditions living happy lives (How et al., 2019; Johnson et al., 2018). Some parents also joined parent groups and disability organizations to extend their social support (Johnson et al., 2018; McKechnie & Pridham, 2012; McKechnie et al., 2015).

Healthcare Planning. Parents also took comfort in planning for the future. They focused on the logistical health consequences of the diagnosis, joined healthcare waitlists, and planned postnatal care so they could be actively involved in upcoming healthcare decisions (Carlsson et al., 2015; Johnson et al., 2018; McKechnie & Pridham, 2012; McKechnie et al., 2015). Others reflected on their personal health and began eating better and exercising (Im et al., 2018).

Perspective-Taking. As another strategy, parents reexamined their perspectives of the diagnosis.

Some utilized religion and began to view their baby as a blessing from a higher power (Goff et al., 2013; Im et al., 2013), while others actively worked to change their idealized future to better align with the diagnosis (Clark et al., 2020; How et al., 2019; McKechnie et al., 2015). These parents emphasized gaining rather than losing and focused on the essential responsibility of raising the child, identifying themselves as parents and embracing their parental role (How et al., 2019; Lou et al., 2020; McKechnie et al., 2015).

Discussion

This systematic review of 14 qualitative studies explored the psychological processes of prospective parents after receiving a fetal diagnosis. The review found that receiving a prenatal diagnosis marks a multiplex adjustment period for parents and adds an unexpected psychological burden as they absorb the news. At the initial diagnosis, parents often experienced mourning and shock. Past work suggests that these reactions are common for parents, and they are not alone in these feelings (Staham et al., 2000) as the initial diagnosis is the most emotionally challenging time for parents (Chaplin et al., 2005). Beyond the first diagnosis, parents in the present review progressed through a multifaceted adjustment process filled with dynamic, complicated emotions. Consistent with prior work, parents in the present review differed in processing time as they accepted the child as an individual (Chaplin et al., 2005; Lou et al., 2017) and oriented themselves to how the diagnosis shaped their present and future (Johnson et al., 2020; Statham et al., 2000). Outside factors including social support and coping strategies influenced parents' individual adjustment trajectories.

A mental shift is common for prospective parents. Past work has shown that the transition to parenthood lowers new parents' psychological well-being, even for those with typically develop pregnancies and high self-esteem prior to becoming a parent (Chen et al., 2020). However, parents who receive a fetal diagnosis are at an especially increased mental health risk (Cole et al., 2016) as they shift their mindsets and prepare for the future.

Given the emotional adjustment occurring in these pregnancies and the influence of external factors documented in the present review, parents may benefit from appropriate care and support during this period to boost positive influencing factors

the present review. Strengthening protective factors in this population is especially imperative as parents may be at risk for long-term psychological distress as children born with a fetal abnormality have an increased risk of altered developmental outcomes and disabilities throughout their lifespan (Liu et al., 2016; Love et al., 2011) and parents of children with disabilities often show decreased psychological health (Olsson & Hwang, 2008).

One possibility for a reinforced protective support is through healthcare providers. The present review and past literature show that parents with fetal diagnoses often experience negative, insensitive, and uninformed medical care (Chaplin et al., 2005; Stock et al., 2019), but literature suggests that healthcare providers may be ill-prepared and receive little training in parent practices post-diagnosis (Johnson et al., 2020; Luz et al., 2017). Despite this, parents strongly rely on and desire genuine, trusting relationships with their healthcare team (Oulton et al., 2020), and parents in the present review who received supportive care from their healthcare team felt more comfortable and prepared. To address gaps in provider quality, health organizations may want to consider updating and expanding parent resources and encourage healthcare professionals to partake in additional professional development and training on parent support practices and fetal abnormalities to better support families in the perinatal period.

As evidenced in the present review and prior work (Coffman & Ray, 2002; Kugler & Farmer, 2015), targeted social networks also offer a promising route for a bolstered protective role. In addition to parents' immediate social circles, findings suggest advantages to participation in formal social outlets such as support groups, especially those with similar perinatal experiences. Parents in past literature who participated in parent groups described these relationships as imperative for their adjustment to parenthood as it provided a space to discuss their shared experiences and challenges with new parenting (Glavin et al., 2017). Parents who receive fetal diagnoses may benefit from such social opportunities to connect with other families with shared experiences.

A third, innovative approach to strengthening protective factors is the addition of psychological professionals to prospective parents' support teams. Literature suggests that parents are best supported by a multidisciplinary team of healthcare and psy-

chological professionals (Catlin et al., 2008; Statham et al., 2000), and as such parents may benefit from psychological support as they process the diagnosis. Recent work on mindfulness interventions (Reid et al., 2016), group prenatal care (Ickovics et al., 2019), grief support (Navidian et al., 2017), and other psychological counseling (Rohde et al., 2008) indicate promising results for perinatal parent populations. Pretest counseling has also been demonstrated as beneficial to help emotionally prepare parents for prenatal screening results (Dorner et al., 2020).

Limitations and Conclusion

There are some limitations in this review. First, while efforts were made to conduct a thorough, comprehensive search and selection of literature, additional studies may have been published since the initial searches were performed and were not included in the present selection. Similarly, the analysis process may differ between researchers. Although procedural steps are detailed, it is possible that others may utilize different coding arrangements and judgements. Additionally, although qualitative studies were included in the present review, quantitative data may also provide valuable insights. Future work in this area may want to perform an analysis of quantitative findings or synthesize a combination of both qualitative and quantitative literature. Studies in this review covered a wide range of countries. It is important to note the influence of culture in each target population, which may shape study results including individual responses, coping, and perspectives. Future reviews may benefit from narrowing the focus to a more homogenous selection of countries, while further empirical work is needed to explore fetal diagnoses and available resources across cultures and geographic regions.

Receiving a fetal diagnosis is life-altering news for families. The present review suggests that prospective parents have similar initial reactions to prenatal diagnosis, but the subsequent adjustment process is shaped by various influencing factors and external characteristics. Parents who have strong protective factors, such as supportive social networks and sensitive, informed healthcare support may have improved experiences and adjustment. Findings suggest the benefit of providing improved medical, psychological, and social resources to parents after a fetal diagnosis. Taken together, these findings provide deeper un-

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derstanding of parent experiences and related factors and indicate directions for future parent support.

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Table 1*Characteristics of Included Studies*

Author, Year, and Country	Stated Aim	n	Fetal Diagnosis	Qualitative data source	Quality
Carlsson <i>et al.</i> (2015) Sweden	Explore parental experiences and need for information following a prenatal diagnosis	11	Congenital anomaly	Qualitative interviews	<i>High</i>
Carlsson <i>et al.</i> (2017) Sweden	Explore written statements where parents communicate their experience with a prenatal diagnosis	18	Congenital anomaly	Search of online discussion responses	<i>High</i>
Clark <i>et al.</i> (2020) United States	Describe the adjustment process of parents after receiving a prenatal diagnosis	42	Down Syndrome	Qualitative interviews	<i>High</i>
Côté-Arsenault & Denney-Koelsch (2011) United States	Investigate the parents' pregnancy experiences to gain insight into their needs	8	Lethal Fetal Diagnosis (e.g. Trisomy 13 or 18, Anencephaly)	Qualitative interviews	<i>High</i>
Goff <i>et al.</i> (2013) United States	Explore parent experiences upon receiving a prenatal diagnosis	46 (prenatal sample)	Down Syndrome	Online survey with open-ended questions	<i>Moderate</i>
Hickerton <i>et al.</i> (2011)	Investigate how parents experience a pregnancy with a	9	Genetic conditions	Qualitative interviews	<i>High</i>
How <i>et al.</i> (2019) Australia	Explore the views of fathers towards prenatal diagnosis	5	Down Syndrome	Qualitative interviews	<i>High</i>
Im <i>et al.</i> (2018) South Korea	Explore the pregnancy experience of mothers who receive a prenatal diagnosis	12	Congenital heart defect	Qualitative interviews	<i>High</i>
Johnson <i>et al.</i> (2018) United Kingdom	Explore parent experiences with a prenatal diagnosis and understand how family care could be improved	20	Dysmelia	Qualitative interviews	<i>High</i>
Lokmic <i>et al.</i> (2017) Australia	Investigate the views and experiences of parents who received a prenatal diagnosis	5	Lymphatic malformation	Qualitative interviews	<i>Moderate</i>
Lou <i>et al.</i> (2020) Denmark	Explore how parents with a prenatal diagnosis experience the diagnostic process and make decisions	9	Down Syndrome	Qualitative interviews	<i>High</i>
McKechnie & Pridham (2012) United States	Examine the retrospective accounts of parents who experienced a prenatal diagnosis	16	Congenital heart defect	Qualitative interviews	<i>High</i>
McKechnie <i>et al.</i> (2015) United States	Examine how parenting develops after receiving a prenatal diagnosis	37	Fetal anomaly	Qualitative interviews	<i>High</i>
O'Connell <i>et al.</i> (2019) Ireland	Investigate the experiences of pregnancy and prenatal care of mothers who continue pregnancy after receiving a fetal diagnosis	4	Anencephaly	Qualitative interviews	<i>High</i>

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Table 2

Summary of Themes

Study	Initial Reactions					Processing Period		
	Shock	Grief	Anger/Confusion	Fear	Guilt	Acceptance	Anxiety	Attachment/Hope
Carlsson <i>et al</i> (2015)		X	X	X		X	X	
Carlsson <i>et al</i> (2017)	X	X	X		X	X	X	X
Clark <i>et al</i> (2020)	X	X			X	X	X	X
Côté-Arsenault & Denney-Koelsch (2011)	X	X			X			X
Goff <i>et al</i> (2013)	X		X			X	X	
Hickerton <i>et al</i> (2011)	X	X	X		X	X	X	
How <i>et al</i> (2019)	X	X				X	X	
Im <i>et al</i> (2018)	X	X	X	X	X	X	X	X
Johnson <i>et al</i> (2018)	X	X					X	
Lokmic <i>et al</i> (2017)	X				X			
Lou <i>et al</i> (2020)		X		X		X	X	X
McKechnie & Pridham (2012)	X	X	X			X	X	X
McKechnie <i>et al</i> (2015)		X		X		X	X	X
O'Connell <i>et al</i> (2019)	X	X					X	X

GASPAR

Table 2 (continued)

Summary of Themes

Study	Influencing Factors							
	Social Interactions				Coping Strategies			
	Healthcare		Friends and Family		Information-Gathering	Experiential Knowledge	Healthcare Planning	Perspective-Taking
Positive	Negative	Positive	Negative					
Carlsson <i>et al</i> (2015)	X	X			X	X	X	
Carlsson <i>et al</i> (2017)		X	X	X	X	X		
Clark <i>et al</i> (2020)		X	X	X	X	X		X
Côté-Arsenault & Denney-Koelsch (2011)	X	X	X	X				
Goff <i>et al</i> (2013)	X	X	X					X
Hickerton <i>et al</i> (2011)	X	X	X	X				
How <i>et al</i> (2019)	X	X		X		X		X
Im <i>et al</i> (2018)	X	X			X		X	X
Johnson <i>et al</i> (2018)		X			X	X	X	
Lokmic <i>et al</i> (2017)		X			X	X		
Lou <i>et al</i> (2020)	X	X			X			X
McKechnie & Pridham (2012)	X		X		X	X	X	
McKechnie <i>et al</i> (2015)	X	X	X	X	X	X	X	X
O'Connell <i>et al</i> (2019)	X	X	X	X	X	X		

PARENT PSYCHOLOGICAL ADAPTATION

Figure 1

PRISMA Flow Diagram

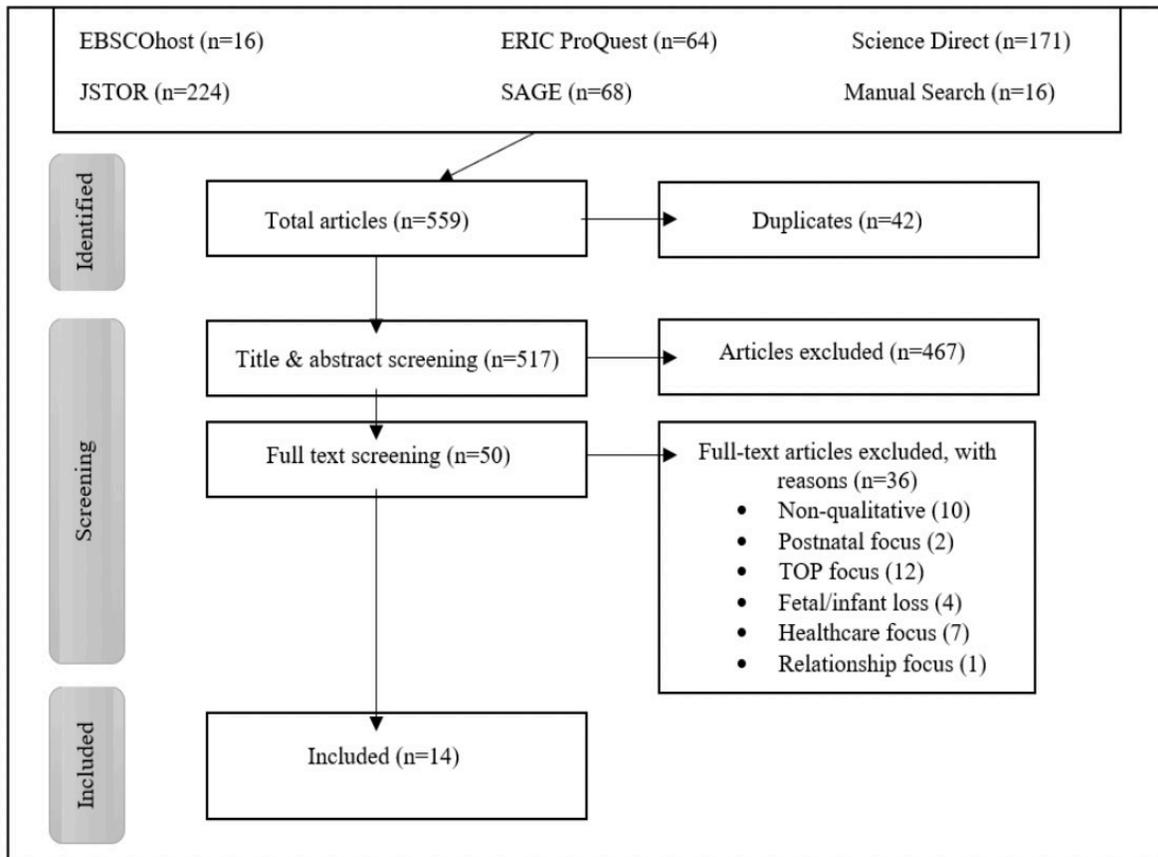


Figure 2

Model of Parent Psychological Processing After a Fetal Diagnosis

