

Partner mental health as a mediating force in the care of infants with congenital anomalies

Abstract

Congenital anomalies affect approximately three to six percent of all live births worldwide and their impact on the mental health of mothers has been increasingly recognised over the past two decades. Yet a persistent blind spot runs through this literature: the fathers, partners and co-caregivers who stand beside these mothers every single day. When a partner is psychologically unravelling silently, without clinical acknowledgement, the mother loses her most proximal source of support at precisely the moment she needs it most. This study argues that partner mental health is not a secondary concern in congenital anomaly care it is a mediating variable in maternal outcomes. Drawing on the theoretical frameworks of ambiguous loss, disenfranchised grief and dyadic coping and on evidence from perinatal psychiatry and neonatal care research, the mechanisms through which unaddressed partner distress compounds maternal psychological burden have been mapped. A three-zone Dyadic Burden Model has been proposed as a clinical organising framework, existing validated assessment tools are reviewed and practical recommendations for couple-inclusive care pathways are outlined. The family is an ecosystem. Until it is treated as one, interventions will remain structurally incomplete.

Keywords: congenital anomalies, psychological uncertainty, childhood, foetal anomaly

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Introduction

A child is born with a congenital heart defect. Surgeons operate. Neonatologists monitor. Nurses chart vital signs through the night. Someone, eventually, screens the mother for depression. Nobody asks the father how he is sleeping.¹ This is not a rhetorical scenario. It is routine clinical practice in tertiary care hospitals across the world and it reflects a structural gap that this study aims to bring into focus. Congenital anomalies, structural or functional disorders present at birth, affect between three and six percent of live births globally, accounting for an estimated 295,000 neonatal deaths annually.² The survivors and the families who receive them enter a world that medicine has not adequately prepared for their emotional realities. Advances in prenatal screening, while clinically invaluable, paradoxically increase rather than eliminate psychological uncertainty for expectant parents, generating levels of emotional distress that technological sophistication alone cannot address.³ Even for conditions such as hypospadias, antenatal detection now occurs at a mean gestational age of 26 weeks, creating a prolonged window of parental psychological uncertainty and anticipatory distress well before birth, a period for which no structured psychological support currently exists.⁴

The mental health consequences for mothers in this situation are increasingly documented. Rates of clinical depression, post-traumatic stress and complicated grief are substantially elevated compared to mothers of typically developing infants.⁵ The discovery of a foetal anomaly precipitates a spectrum of intense and conflicting emotions, including shock, guilt, anxiety and anticipatory grief that begin at diagnosis, often well before birth.⁶ Yet even this maternal focus, welcome as it is, reproduces a narrowness of its own. It positions the mother as the sole patient, the father or partner as support staff and the couple as a backdrop rather than a unit of care.

This is a study about that backdrop. More specifically, it is about what happens to the support a mother depends on when her partner is carrying an equally heavy, equally unacknowledged weight and nobody has noticed. Clinical accounts from antenatal counselling

sessions document this phenomenon directly while the mother asked repeated questions, the father sat completely still, saying nothing; he is present in the room but already unreachable.⁷ Partner psychological distress is not merely a welfare concern in its own right; it functions as a mediating variable that directly shapes the mother's capacity to cope, bond and recover. Ignoring it is not just clinically incomplete. It is, in effect, undermining the interventions already available.

The neglected figure: evidence on partner mental health

What the numbers tell us: A landmark meta-analysis found that approximately ten percent of fathers experience depression during the perinatal period.³ This figure rises considerably in the context of infant illness and medical complexity. The same analysis found that paternal and maternal depression are significantly correlated, with a pooled effect size suggesting that a depressed father substantially elevates the risk of a depressed mother. Paternal postnatal depression independently predicts adverse emotional and behavioural outcomes in children at three and a half years, not through genetics, but through the quality of fathering and relational atmosphere in the home.⁸

In the specific context of neonatal intensive care, Arockiasamy and colleagues (2008) conducted a qualitative study in Pediatrics documenting fathers' experiences in the NICU as a 'search for control' characterised by profound helplessness, exclusion from clinical communication, guilt and grief that they felt they had no permission to express.⁹ What emerges from these accounts is not fragility but suppression: men who were actively managing acute psychological distress by performing composed strength for their partners, while receiving no support themselves.

Why partners are systematically missed: The clinical architecture of perinatal and neonatal care is built around the mother-infant dyad. Obstetrics hands care to neonatology; the index patient is always either the mother or the infant; the father or partner moves through the hospital as a visitor, a caregiver, a decision-maker but not as a patient. Screening protocols, where they exist at all, are directed at

mothers. Partners are rarely offered psychological assessment, rarely included in follow-up appointments and rarely seen by social work or psychology services unless they present with a crisis that is impossible to overlook.

Added to this structural exclusion is the weight of the cultural script. Across most societies, and emphatically in patriarchal or collective-family structures, men are expected to hold the emotional architecture steady. Expressing psychological need is read as abandoning the mother to cope alone. Therefore, partners perform stability while quietly disintegrating, a pattern Doka (2002) would recognise immediately as the terrain of disenfranchised grief: loss and distress for which there is no recognised social permission to mourn.¹⁰

Disenfranchised grief and ambiguous loss: Pauline Boss (1999) developed the concept of ambiguous loss to describe situations in which grief cannot be cleanly resolved because the loss itself is not clear-cut.¹¹ A child with a congenital anomaly is not lost, the child is present and loved, but the child the parents had imagined is gone. This grief is recursive, resurfacing at developmental milestones, medical setbacks and social comparisons. Even before birth, parents may engage in what has been termed ‘conditional bonding’, consciously or unconsciously withholding full emotional investment in the pregnancy as a protective response to diagnostic uncertainty, a mechanism that, while psychologically understandable, generates

its own compounding burden of guilt and grief.¹ For mothers, this experience has begun to be named and written about. For fathers and partners, it remains largely without language.

Doka’s (2002) framework of disenfranchised grief is equally instructive. When a form of loss is not publicly acknowledged, when there are no rituals, no socially sanctioned space for grief, no one asking how the father is, the grief does not diminish. It goes underground, appearing instead as withdrawal, irritability, somatic complaints, overwork or substance use. These are the signals clinical teams are not trained to read as grief and partners are not empowered to name.

The mechanism: how partner distress amplifies maternal burden

Support Depletion: The mother’s primary buffer against the weight of caring for an infant with a congenital anomaly is, in most families, her partner. When that partner is psychologically depleted, the buffer collapses. This is not metaphorical (Figure 1). The mechanism is well-described in the broader caregiving literature. It has particular relevance here: emotional availability, active listening, practical co-management and what developmental psychologists call co-regulation, the capacity of one person to help stabilise another’s nervous system through their own calm presence, all diminish under conditions of unaddressed psychological distress.

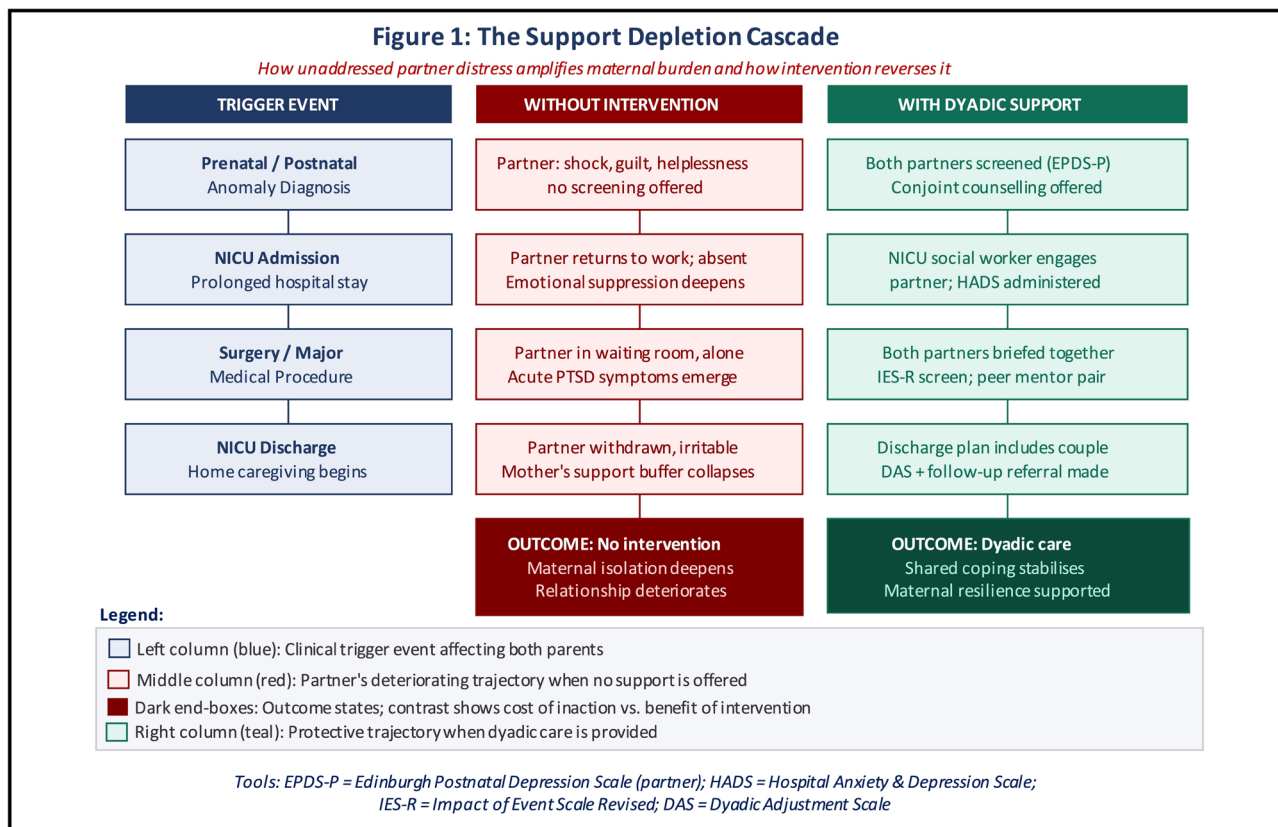


Figure 1 The support depletion cascade: conceptual flowchart

A vertical flowchart depicting the progression from infant diagnosis to parental psychological outcomes. Parallel pathways illustrate maternal and partner trajectories. Unaddressed partner distress contributes to reduced emotional availability, relationship strain, increased caregiver burden and maternal isolation. An alternative pathway demonstrates improved dyadic coping and stabilisation of maternal outcomes when partner distress is identified and supported.

The mother, already carrying grief, guilt, physical exhaustion and clinical anxiety, finds herself also managing a partner who has shut down, is avoiding the NICU, snaps at small things, or is simply absent even when present. The effect is compounding: her isolation deepens, her burden increases and she often redirects emotional energy toward protecting the partner from further distress, when she has none to spare.

Dyadic coping: the theoretical foundation: Bodenmann's Dyadic Coping Model offers perhaps the most useful clinical framework for understanding how couples respond to prolonged medical stress.¹² The model distinguishes between individual coping what each person does privately to manage their own distress and dyadic coping, which is the joint, interactive process by which couples regulate stress together. Positive dyadic coping includes supportive coping (one partner actively helping the other), delegated coping (one partner taking over tasks) and common coping (facing the challenge together as a shared project). Negative dyadic coping includes hostile coping, ambivalent coping (going through the motions without genuine support) and superficial reassurance.

When a partner's mental health deteriorates, dyadic coping almost inevitably shifts from positive to negative. The couple that once talked through their fears together now communicates through silences and practicalities. Shared meaning-making, which Bodenmann identifies as one of the most protective functions of couple coping, breaks down. The clinical consequence for the mother is not just the loss of support, it is the loss of a shared narrative about what is happening to their family, which is itself a profound psychological resource.

Relationship deterioration as a secondary stressor: The research literature on parents of children with congenital and chronic conditions documents elevated rates of relationship distress, marital conflict and role confusion.¹³ Financial pressure, typically absorbed by the partner who returns to work earliest, creates an additional asymmetry: the partner is absent from the clinical environment not always by choice or avoidance, but by economic necessity while the mother remains at the hospital, increasingly alone. The cumulative effect of these pressures is a relationship that both partners may feel is failing them, without either having the words or the bandwidth to address it.

The cultural dimension: one story, many contexts: It would be a mistake to describe this phenomenon as though it plays out identically across the world. The specific form that partner exclusion and distress takes is shaped profoundly by cultural context and nowhere more so than in low- and middle-income countries, which carry the 94% of the global congenital anomaly burden.⁶ The research infrastructure mirrors this inequity: even in condition-specific literature, studies from low-resource settings remain a single-digit minority, with low-resource regions limited by infrastructure and technical expertise: a gap that applies equally to psychological support as it does to diagnostic imaging.⁴

In South Asian contexts, the partner often occupies a mediating position between the mother and her extended family or in-laws, managing blame narratives, fielding questions about causation that carry implicit moral weight and absorbing stigma before it reaches the mother. In patriarchal settings, the partner's acceptance of the infant, particularly where the anomaly disrupts gendered expectations, directly shapes the mother's ability to bond with and advocate for her child. A father who is himself struggling with shame or grief but cannot name it may express that distress through withdrawal, denial, or, in some cases, pressure on the mother that compounds her suffering substantially. Financial devastation, cultural prohibition and legal variability across jurisdictions further shape how partners process and

express their distress, factors that sit silently in the background of nearly every counselling encounter.⁷

These are not edge cases. They are the daily reality of the majority of families affected by congenital anomalies globally. Yet the research literature that might inform culturally responsive intervention is dominated by data from high-income, Western, typically heterosexual, two-parent families, a representation problem that limits both the generalisability of findings and the usefulness of proposed solutions in contexts where they are most urgently needed.

What exists and what is missing: tools, gaps and opportunities

Assessment Tools Available in the Literature: The good news is that validated tools exist and can be meaningfully adapted or repurposed for screening a partner's mental health in this context. The Edinburgh Postnatal Depression Scale (EPDS), originally developed by Cox, Holden, and Sagovsky (1987) for maternal screening, has since been studied in partner populations and shown acceptable psychometric properties when used with fathers in the perinatal period.¹⁴ The Hospital Anxiety and Depression Scale (HADS), developed by Zigmond and Snaith (1983), is a brief, well-validated instrument that requires no clinical training to administer and is particularly suited to medical settings where partners are most likely to be encountered.¹⁵

For assessing the relational dimension, the dyadic coping capacity that mediates maternal outcomes, the Dyadic Adjustment Scale (DAS), developed by Spanier (1976), remains the most widely used and robustly validated tool in the couple psychology literature.¹⁶ It assesses dyadic satisfaction, cohesion, consensus and affective expression across 32 items and has been used in research involving parents of medically complex children. For trauma-related symptoms, relevant in families navigating emergency surgical intervention or prolonged NICU stays, the Impact of Event Scale (Horowitz, Wilner, and Alvarez, 1979) provides a brief and accessible measure of intrusion and avoidance symptoms that can be used with both partners.¹⁷

None of these tools, it must be said, has been validated specifically for partners of infants with congenital anomalies as a primary study population. That validation work represents one of the most actionable research gaps in this field.

What Is Missing: The structural gaps run parallel at three levels. In research, there are almost no longitudinal dyadic studies that track both partners as primary participants over the trajectory of congenital anomaly care from prenatal diagnosis through early childhood. Partner mental health, when measured at all, is typically a secondary or exploratory variable rather than a primary outcome. Data from Low- and Middle-Income Countries (LMICs) are sparse. Studies involving same-sex couples, single mothers with equivalent primary support figures or non-Western family structures are essentially absent.

In clinical practice, no standard protocol exists for partner psychological assessment at any of the key transition points in congenital anomaly care: diagnosis, admission, surgery, discharge or follow-up, a gap that mirrors the broader absence of standardised antenatal counselling frameworks, a deficiency acknowledged even in recent surgical classification literature.⁶ Partners are present in hospitals, but they are functionally invisible to the psychological care infrastructure.

In policy, parental leave frameworks rarely protect both partners equally in the context of infant illness, creating structural conditions in which one caregiver is economically compelled to be absent from the clinical environment. Mental health coverage for partners of medically

complex infants is often excluded from insurance frameworks that cover only the index patient and their primary caregiver.

Toward a Dyadic Model of Care: Solutions and Recommendations

Screening Both Partners, Routinely: The most immediate and achievable intervention is also the most obvious: clinical teams should

screen both parents or co-caregivers for psychological distress at each key transition point, using validated tools that require no specialist training to administer. The EPDS (adapted for partner use), the HADS and where relational concerns are present, a brief dyadic coping screen should be integrated into standard care protocols in neonatal and paediatric surgical units. A five-minute paper-based screen costs nothing and can open a door that many partners will not have known existed (Figure 2).

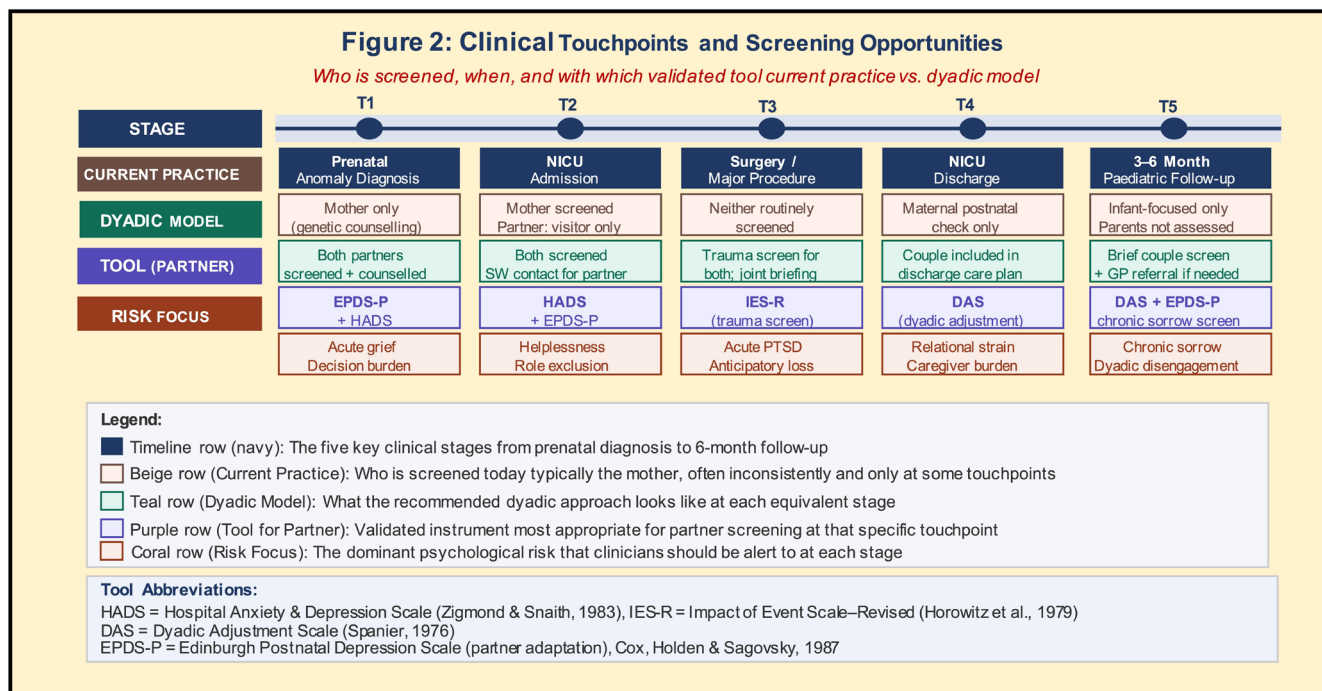


Figure 2 Timeline of clinical touchpoints and screening opportunities

A horizontal timeline from prenatal diagnosis to six months post-discharge, highlighting key clinical events (prenatal diagnosis, NICU admission, surgery, discharge and follow-up). At each stage, the figure indicates current screening practices (primarily maternal), recommended dyadic screening (both partners) and appropriate assessment tools (for example, EPDS-partner at admission, HADS at surgery and discharge, DAS at three-month follow-up and IES-R where PTSD risk is elevated).

Including Partners in Psychoeducation and Counselling: Psychological support in congenital anomaly care, where it exists, is typically offered to the mother alone, or positions the partner as a participant in the mother’s support rather than a person with needs of their own. A dyadic model of care would include conjoint psychoeducation sessions at key moments: at diagnosis, before and after major procedures and at discharge. These sessions would explicitly name the fact that both parents are experiencing grief, that this grief looks different in different people and that the relationship between them is itself a resource that needs tending.

Peer support programs, increasingly recognised as effective in perinatal mental health contexts, should be extended to couples and to fathers and partners specifically, not only to mothers. The evidence from chronic illness caregiving research suggests that same-experience peer contact is valued by partners who feel that no one else can understand what they are living through.

Training Clinical Teams to See the Whole Family: Neonatal nurses, paediatric surgeons and social workers are not currently trained, in most healthcare systems, to identify or respond to paternal or partner psychological distress as a clinical concern. Brief training

in how distress presents in partners, how to invite disclosure without intrusiveness and when to refer is a low-cost, high-leverage intervention. NICU social workers, in particular, are well-positioned to conduct brief relational assessments of both parents and to initiate referrals to couple-focused support services.

Adapting for LMIC Contexts: In settings where specialist mental health services are unavailable or inaccessible, community health workers can be trained to identify and respond to signs of partner distress within existing maternal and child health frameworks. Mobile and digital mental health tools, adapted for low-resource contexts, offer scalable reach. Cultural adaptation specifically addressing the gendered stigma that surrounds male emotional disclosure in many societies is not optional, it is the difference between an intervention that gets used and one that sits on a shelf.

A Conceptual Anchor: The Dyadic Burden Model. As a clinical and research organising framework, we propose the Dyadic Burden Model, which conceives of the couple as carrying three distinct but interacting zones of burden. Zone A represents the individual burden of the stressors unique to each person: the mother’s physical recovery and infant bonding; the partner’s financial responsibility and

emotional suppression. Zone B represents the shared burden of grief, decision-making stress and anticipatory mourning that both carry together, but which may not be communicated between them. Zone

C represents relational burden that the relationship itself is carrying: conflict, withdrawal, role confusion and the quiet erosion of intimacy and mutual recognition (Figure 3).

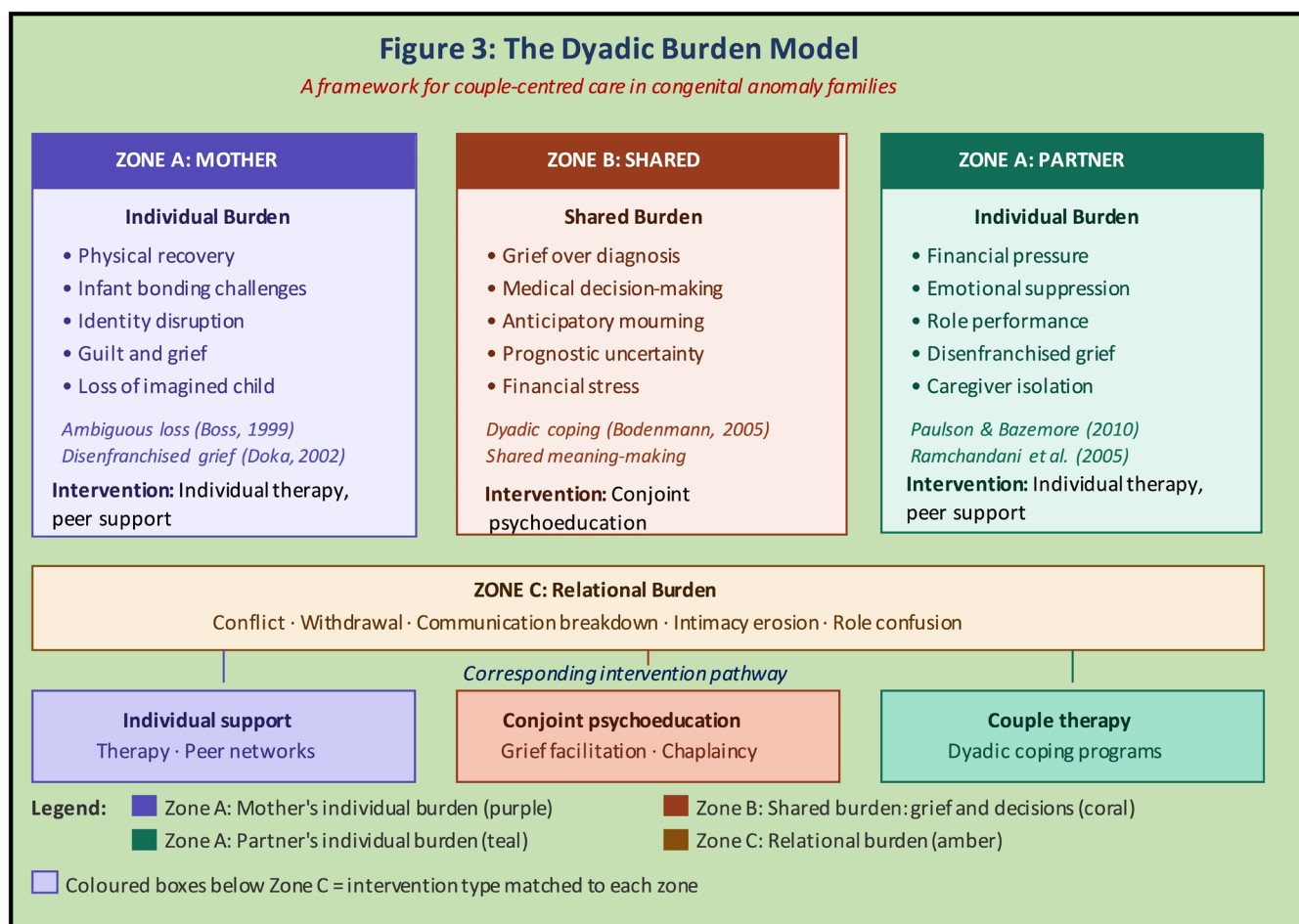


Figure 3 The dyadic burden model: three-zone diagram

A Venn-style diagram illustrating three overlapping domains of burden. Zone A (Individual Burden) includes maternal factors (physical recovery, infant bonding, identity disruption) and partner factors (financial pressure, role performance, emotional suppression). Zone B (Shared Burden) encompasses grief, medical decision-making and anticipatory mourning. Zone C (Relational Burden) represents communication breakdown, withdrawal and intimacy erosion. Arrows indicate corresponding intervention strategies: individual support, conjoint psychoeducation and couple therapy.

Each zone requires a different mode of intervention. Individual burden responds to individual therapy, peer support and culturally adapted psychoeducation. Shared burden responds to conjoint sessions, facilitated grief work and communication-focused interventions. Relational burden responds to couple therapy and dyadic coping programmes. The model is not intended as a rigid taxonomy but as a clinical map, something that allows a NICU social worker or a perinatal psychologist to ask: where is this family most stuck right now and what kind of support does that require?

Conclusion

Medicine has made extraordinary strides in diagnosing, repairing and managing congenital anomalies. The infant who would not have survived thirty years ago now does. That is a genuine triumph and it is not diminished by what this paper is pointing to. What this study is pointing to is the other person in the room, or more often, the corridor outside the room, on a phone call to work, trying to hold together

the finances and the family and the performance of composure while something inside them breaks quietly and continuously.

The mother is the identified patient in perinatal mental health. She should be. But the partner is the environment in which she recovers or fails to. A distressed partner is a compromised environment. We have the tools to change this. We have the theoretical frameworks, the validated instruments and the clinical touchpoints. What we have lacked, so far, is the will to make the whole family visible. It is time we did.

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None.

Conflict of interest

We declare that we have no conflict of interest.

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