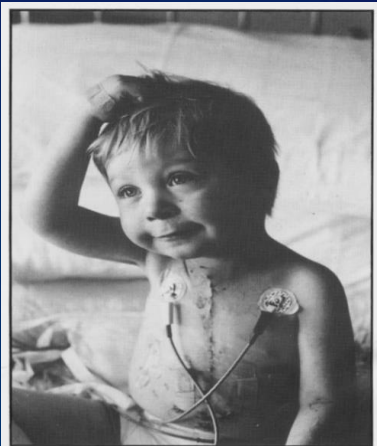


The grief experienced by parents in response to their living child
with a disability that can only be treated with palliative surgery.

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Picture by Helga Sahwe.

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Understanding the child's condition: hypoplastic left heart syndrome (HLHS)



- ♥ HLHS is a congenital heart defect
- ♥ The child's condition is a very serious
- ♥ It results in an under-development of the left side of the heart and is associated with:
 - ♥ Possible, but likely, neurological deficits
 - ♥ Other medical complications
 - ♥ Treatment is palliative surgery and the child will die of heart failure, possibly during childhood
 - ♥ Parents do not know whether to anticipate a longer life or a very short life with the child

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The Study Design

♥ Mixed methods study incorporating a pragmatic paradigm

Methods: interviews and psychometric tests

1. Interviews: semi-structured

Explored loss at: diagnosis, intensive care, hospital and home.

Methods: Psychometric tests

- 2. Psychometric tests:
 - ♥ **TRAUMA: SCID-CV** (First, et al., 1997). The Structured Clinical Interview for Diagnosis)
 - ♥ **TRAUMA: PCL-C** (Weathers et al., 1993: *The Psychological Checklist, Civilian*)
 - ♥ **BURNOUT: MBI** (Maslach & Jackson, 1981: *The Maslach Burnout Inventory*)
 - ♥ **FAMILY IMPACT: IOF** (Stein & Jessop, 1984): *The Impact on Family*
 - ♥ **MEASURE OF FUNCTION: RAHFC: MOF** (Dossetor et al., 1996: *The Royal Alexander Hospital for Children, Measure of Function*)

Participants

Eligibility:

Parents of living children with HLHS in Victoria who had chosen surgery (22 children)

Cohort:

29 parents: 13 couples; 16 mothers plus 13 fathers (16 children)

DIAGNOSIS

Two time periods of the diagnosis: in-utero or after birth

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Intense loss and shock

We were distraught and shocked beyond belief.

- Previous losses were also recalled
- Parents whose infant was diagnosed “in-utero” had more time for “griefwork” and for “restoration”
- Parents whose infant was diagnosed after birth had an intense dose of grief then grieving was curtailed.

Loss complicated by traumatic stress



*I thought I had been hit by freight train
I couldn't take much in. I was afraid. I felt shut down.*

The majority of parents that the diagnosis was traumatic and 15/16 mothers and 9/13 fathers developed an initial traumatic reaction and then continued to develop PTSD (SCID).

The difference in trauma responses between mothers and fathers was not statistically significant ($p = 0.85$, Fisher's exact test).

Grief at diagnosis

Impact: Loss, secondary loss, trauma and other stressors. Movements towards restoration

Parents' grieved and then curtailed their grief work, although some grief responses burst forward. The parents' focus was on the survival of the infant.

What may help these parents?

- *Clear communication*
- *Parents need basic supports at this time. They do not have resources to deeply explore their feelings as parents flooded with emotion*
- *Think basic supports: practical help, psychological first aid-safety, warmth, drink, simple listening without asking parents to delve too deeply Staying with emotion*
- *Honoring of parents' capacities to deal with this loss*

• INTENSIVE CARE



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Losses continued to unfold:

admission to ICU

loss of intimacy with infant:

The hospital owned my child. I couldn't do anything with her. I had no part.

I looked at my child and I thought where do you hold her

The appearance of the infant after surgery

There were medical complications and family loss, such as separation from other children and from partners.

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PICU: Intense loss continued to be complicated by trauma

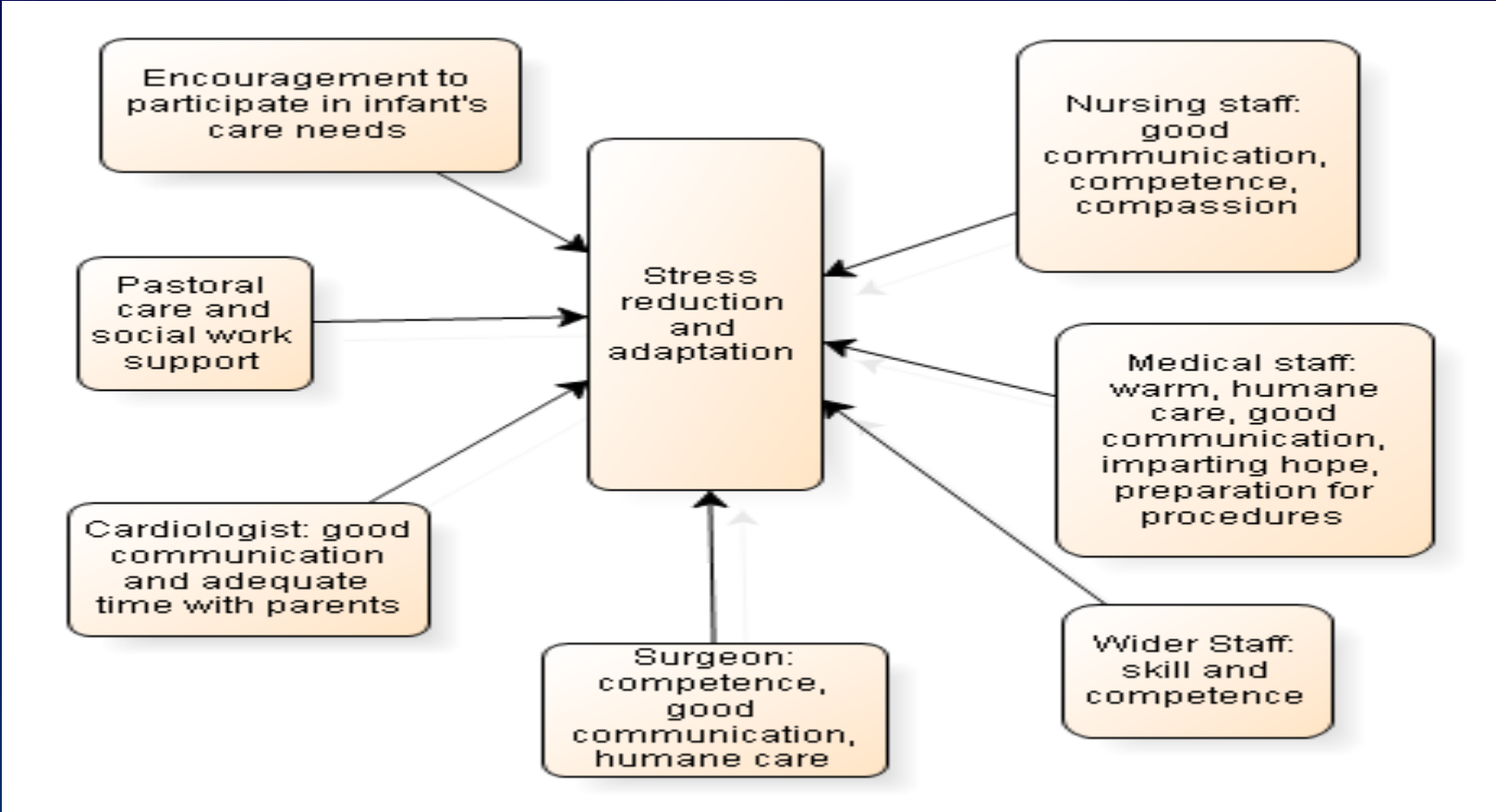
- Loss intersected with traumatic stress

The effects on him have been life threatening. It was incredibly traumatic. He could not find his way around the anxiety and fear.

Grief in the PICU

- *These parents continued to put aside their grieving although grief in response to some stressors broke through.*

PICU : What reduced stress: may have implications for healthy grief at a later time



Other possibilities of support?



- Basic supports and clear communication
- Practical staff support, volunteers, encouraging social support
- Anything that helps parents feel safe: think environment, concern, compassion, interest in parent
- Recognition of how difficult is this time
- Recognition of how stressed parents are at this time, the psychosocial impact and their juggling of traumatic stress, grief
- Recognition of parental resources
- Not appropriate to fully unpack grief at this stage
 - parents have to continue to function and support child

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Clinical implications with grief

- There were peaks of grieving but grief work continued to be inhibited.
Traumatic stress, multiple stressors complicated grieving, as well as the focus on supporting the infant and the family
- Parents straddled hope and fear

WARD

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New loss: mounting loss and grief

- Staff in charge of the infant
- Mothers continued to be separated from their partners, their other children and from home
- Loss of work benefits
- Social isolation

Loss intersected with stress

- ♥ Stressors: child's health, family stressors
- ♥ Traumatic stress

It was too hard. I don't want to think about it... I just wanted to run away and go back later... Part of your brain takes over to stop you thinking... This keeps you going... It is like the brain blocks out part of the main event for some reason.

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What may help?

- Listening to what parents may feel
- Do not unpack too deeply because parents still in survival mode
- Practical supports
- Preparation for home
- Sensitivity to fathers and other children who are likely to be grieving

Grief and impacts upon grieving

- Grief emerged more freely in peaks but still curtailed
- Many parents continued to feel trauma
- Parents experienced many stresses
- Parents continued to put one step in front of the other trying to survive the experience

Adaptation: Some parents continued to mobilize resources

• HOME

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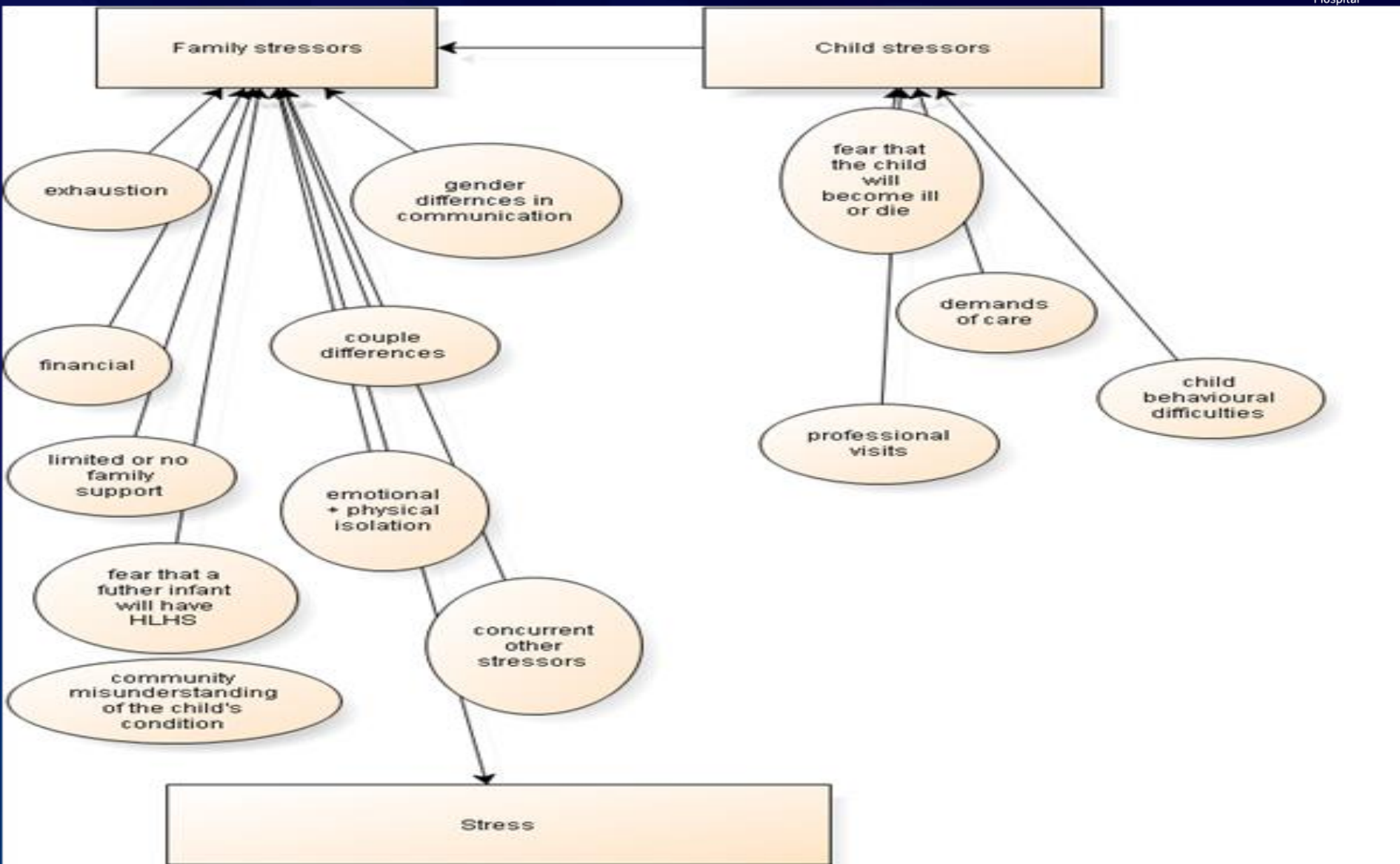


Home Loss

Parents felt great relief and anxiety at discharge
Grief also ebbed and flowed

- ♥ New Losses: child's developmental delay "lost child;" family impact including financial (10 families earned < \$60,000): non-finite loss

Stressors complicated grief



Restoration and Growth

- **Normalization:** *I treat him like another child*
- **Joy in the child:** *Even if I had him for a little while, I thought it was better to have him for that amount than not to have him at all.*
- **Post traumatic growth:** *You do become more compassionate. You learn to value life.*

What may help?

- Counselling: full assessment of loss and family impacts. Helping parents to give voice to the complexity of the experience
- Advocacy for many available supports and team help
- Traumatic stress assistance, for example, filling in the gaps in memory recall
- Honoring of the parents' resources

Grieving Summary

- Parents grieved more freely at home. Think DPM but they may have some inhibited grief
- Juxtaposition of grief and hope
- Many new and secondary losses: non-finite loss
- Disenfranchised loss

Summary

- ♥ Grief emerged in doses and was complicated by stressors and traumatic stress
- ♥ Most grief curtailed in the hospital
- Secondary losses and many stressors were a feature
- ♥ Most parents grieved in a healthy manner at home and the Dual Process Model is useful with limitations
- ♥ Parents found inner strength which sustained them
- ♥ Non-finite loss was ongoing
- ♥ Grieving was unrecognized
- ♥ It is possible that some grieving continued to be curtailed



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good Friday appeal

THE ROYAL CHILDREN'S HOSPITAL

Give that they may grow

A faded scar along Noah's chest is a lasting reminder of life saving heart surgery at The Royal Children's Hospital when he was 5 days old.

Thank you for your support.