





# Withdrawal of Neonatal Life Support: Parent Perspectives

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- **Modern perinatal and neonatal care practices have increased survival of infants that in previous care eras would have perished**
  - **The vast majority of infants admitted to newborn intensive care units (NICU) following birth do well and are discharged home**
  - **Unfortunately for some infants the ultimate outcome is death**

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- How is the decision to withdraw life support in the NICU determined?
  - The literature distinguishes three models of decision making:
    - Paternalistic
    - Informed decision making
    - Shared decision making
  - Current international guidelines support shared decision making; however, parental involvement varies substantially depending on culture and location



Many health care professionals feel inept when discussing bad outcomes or the likelihood of their infant's death with families

What do parents find helpful in this horrific situation?

How do they move forward?



- **Few studies report parents' perceptions regarding the decision to remove their infant from life support**



- **Studies have not fully explored the personal and lived experiences of these parents as they move forward with their lives after their infant's death**



# Qualitative Study

- To explore and describe the experiences of parents who made the decision to withdraw life support from their critically ill infant
- To discover the basic social process parents reveal as life support cessation and subsequent infant death influenced their daily lives
- Recommend a grounded theory to guide clinical nursing practice and interventions with this special population



# Sample Interview Questions

- Tell me what it was like for you when you found out (name) was not going to live
- Tell me how you feel now about your decision
- Tell me what having (name) in your life, even so briefly, has meant to you
- Tell me about your life now, without (name)




# Sample

**n = 15**

- **Online support group**
- **Interviews**
  - face to face (8)
  - telephone (7)
- **Dyads/Individual**
  - Four couples
    - two couples interviewed together
    - two couples interviewed separately
  - Seven individual



# Sample Demographics


#	Age	Sex	Ethnic Identity	Months Since Life Support 	Religion
401	42	F	C	16	Jewish (father's faith)
402	27	F	C	58	Baptist
403	33	F	C	12	Baptist
404	35	F	H	84	Catholic
405*	30	F	C	60	Lutheran
406*	30	M	C	60	Lutheran
407*	37	F	C	36	Catholic
408*	40	M	C	36	Catholic
409	27	F	C	144	Pagan
410	41	F	A	30	Baptist
411	38	F	C	48	Methodist
412*	28	F	C	36	Southern Baptist
413*	28	M	C	36	Southern Baptist
414*	35	F	C	5.5	Catholic
415*	33	M	C	5.5	Catholic

# Sample Demographics

#	Educational Status	Household Income	Prior Losses	Live Births Since/Living
401	Master's	<50K	4	0
402	Some college	<50K	4	1 female
403	College	<100K	0	0
404	15 years	<50K	0	1 female
405*	BS	<50K	0	surviving twin
406*	MS	<100K	0	“
407*	16 years	<100K	0	1 female
408*	16 years	<100K	0	“
409	12 years	<50K	1	1 male/1 female
410	MA	100K	1	surviving twin
411	Post-grad	<50K	0	1 female
412*	Master's	<50K	0	1 female
413*	Master's	<100K	0	“
414*	BA	<100K	0	0
415*	JD	<50K	0	“



# Infant Demographics

Parent ID #s	Infant's Gender	Weeks Gestation at Birth	Age in Months at  Life Support	Time Until Death	Cause of Death
401	M	41	3	7 minutes	unknown
402	M	35	66	30 minutes	CHD
403	F	38	3	37 days	Trisomy 18
404	F	40	12	14 days	Severe HIE
405 & 406	F	25	3	1 hour	ELBW
407 & 408	M	34	12	5 minutes	ACD
409	M	38	9	6 hours	GBS pneum
410	F	36	9	40 minutes	Trisomy 18
411	F	39	11	3 minutes	CHD
412 & 413	M	27	12	40 minutes	ELBW
414 & 415	M	32	2	1 hour	Trisomy 13



# ***“HOLDING A PLACE”***

**A grounded theory of parents bringing their infant forward in their daily lives following the removal of life support and subsequent infant death**



# Prelude to Central Findings



- **The NICU: Residual Trauma**

*“When you have done the life and death in the NICU experience there is a post-traumatic stress quality to your grief that is different”*

# Prelude (con't)



- A Loss Different from all Others

*“It’s often grouped together...I just can’t imagine it’s the same thing...that’s why it’s important for me and others to see her picture”*

# Prelude (con't)



- Membership in Special Subgroup  
*“That is not something you normally hear...people who had similar experiences taking them off life support”*



# Prelude (con't)



- Brevity of Time with the Infant

*“The reality that there was a child and a life that came and went ....seemed to have been lost on a lot of people”*

# Findings Related to Research Question One: Theme One

*How do parents describe their experiences with making decisions about life support for their critically ill infant?*

- *Facing the Decision*





# Subcategories of *“Facing the Decision”*

- No real choice  
*“heartbreaking”, “horrible”,  
“the decision was pretty clear-cut...he wasn’t going to get better”*
- Time as a Family  
*“It was helpful having time alone with her”,  
“It’s important to be a parent to ‘em...before you turn it off”, “I wanted them to spend time with her...hold her, bathe her, whatever...”*

# Verification

- Similar to other studies, parents expressed a need to understand and accept the gravity of their infant's condition
- However, other perinatal loss studies do not report the need on the part of the parents for additional verification of the prognosis on the part of other health care providers
- Study participants able to come to the decision to remove life support only after they were convinced they had exhausted all possible options to ensure their infant's life





# Final Moments

- In some studies, parents held the baby while making the decision to remove their infant's life support
- In other studies, including this one, making the decision to remove life support was separate from the actual act – enabling the parents to determine how that final time with their infant would be spent
- Only regret was actions not taken, not the decision itself



# Health Care Providers

- Interactions with health care providers frequently commented on as being positive in the perinatal loss literature
- Parents in this study divided interactions with health care providers into two time frames
  - During their time in the NICU
    - positive
  - Following the death of their infant and subsequent return to ‘home life’
    - negative

# Findings Related to Research Question Two: Theme Two

*How does the decision to withdraw life support and subsequent death of their infant influence their daily lives?*

- *Life Goes On*





# Subcategories of *“Life Goes On”*

- Listen to Your Heart

*“It’s so personal”, “Figure out what you want to do...what time you need”*

- An Abiding Loss

*“It’s always there”, “A giant void ”, “You learn to function in spite of it”*

- Not Left Out

*“He may not be here physically but he’s always going to be a part of our lives”, “She’s very much alive in our family”*





# No Uniform Strategy

- Perinatal loss studies report a compilation of activities that help some parents while being of no benefit to others supporting the concept that the grief process is an individual one
- Parents in this study describe it as a long, hard process that everyone goes through differently
  - Most helpful was the ability to talk, whenever they needed, about their infant and their experience



# Gender Differences

- Gender differences when it comes to grieving is well documented in the perinatal loss literature
- Both male and female participants in this study commented that their grieving was different; however it did not fall out as a theme in this study
  - Strength of marital bond?
  - Time out from the loss?



# An Ongoing Sense of Loss

- Parents who have lost a newborn report an abiding sense of loss
- In some studies this is referred to as ‘shadow grief’ – where the experience of their infant’s death and attendant feelings remain, ever so subtly
- Parents in this study vividly expressed that their grief, although lessening over time, was much more than ‘subtle’ and was always with them in varying degrees of intensity



# Not Left Out


- Numerous perinatal loss studies affirm parents' need to maintain their deceased infant as an integral part of the family unit
- Study participants found ways to maintain an awareness of the deceased infant for both older and subsequent siblings as well as to create new memories as a family in which the deceased infant remains a part



# Findings Related to Research Question Two: Theme Three

- *Lives Forever Changed*





# Subcategories of “*Lives Forever Changed*”

- New perspective

*“You look at everything a little differently”, “It changed me to be a better person...my life is very rich because of her”*

- Preparing to Meet Again

*“That’s what helps get me through...knowing one day we’re going to be together”*



# Altered World Views

- Women that have experienced a miscarriage have reported experiencing changes in whom and what they were connected to and why
- Similarly, parents in this study recounted a changed perspective regarding what they considered as priorities in their lives
  - Revealed a greater appreciation for the fragility of life



# A Positive Influence

- The ongoing essence of their infant as a part of their world exerted a positive influence on the way in which study parents moved on with their lives
  - Wanted something good to come out of their infant's brief life and what they had to go through
- Reflected in another study on perinatal loss where a mother commented that it was through her daily relationship with her deceased infant that she derived comfort, courage, and a direction for her own life





# Wanting to be Worthy

- Study parents judged their daily actions and behaviors by what they believed would be acceptable to their infant had she or he lived
- Wanting to provide their infant with a proper legacy motivated participants to stay prepared to meet their infant again, reunited in an afterlife or other future time

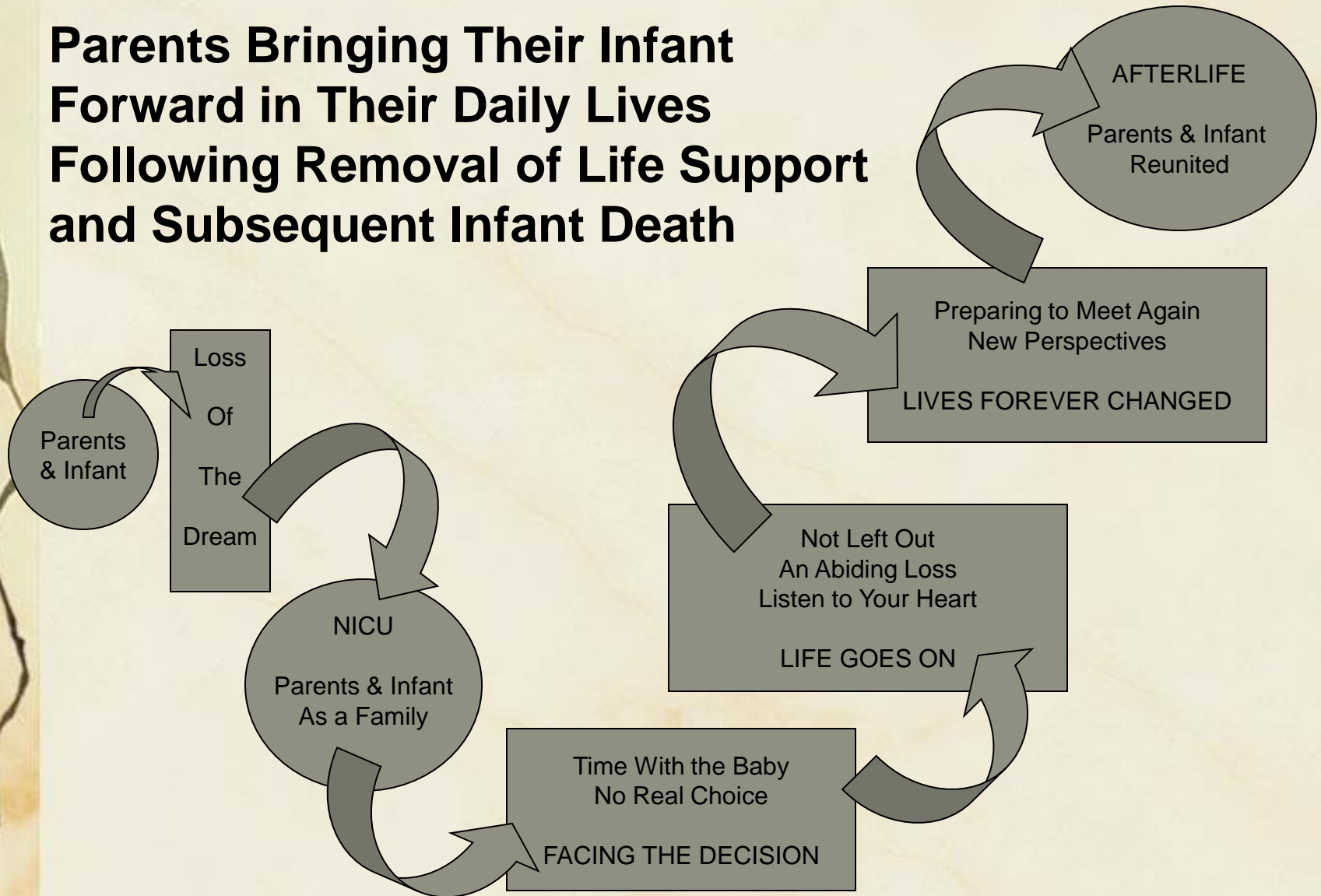


# Reuniting

- Faith plays a significant component in much of the perinatal loss literature
- For the study parents belief in an afterlife where they would be reunited with their infant was a central theme in their healing
  - ‘It’s that belief in an afterlife that makes it easier’...’that is what gets me through...knowing one day we’re going to be together’

# PROCESS OF HOLDING A PLACE

Parents Bringing Their Infant Forward in Their Daily Lives Following Removal of Life Support and Subsequent Infant Death





**Tomorrow will come. The pain will ease. But you will never forget your precious child. It takes hope and time and love for the healing to take place. Remember along the way to accept, but not forget.**

**Sherokee Isle**



# Questions / Discussion



**Thank you...enjoy the remainder  
of the conference..and the beach!**



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