

# **Liminality as a framework to understand parents' experiences of going home after their infants complex cardiac surgery: a conceptual model**

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# Aim of presentation

To present a conceptual framework arising from empirical findings, as an interpretative approach to the phenomenon of liminality, for a group of parents whose infants have recently undergone the first stage of complex cardiac surgery

- Background - CHD
- Context of the study
- Background - liminality
- Findings
- Conceptual framework
- Implications for practice
- Conclusion



Worcester Cathedral

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# Background – congenital heart disease

- Congenital Heart Disease (CHD) occurs in approximately 6-8/1000 live births in UK<sup>1</sup>
- About half of the 5000 babies born with CHD every year in the UK, have life-threatening conditions requiring surgery and life-long follow-up<sup>2</sup>
- In this study, complex CHD included: functionally univentricular hearts and systemic shunt dependent lesions (e.g. hypoplastic left heart syndrome, hypoplastic right heart and tetralogy of Fallot)
- Improvements in surgical, medical and nursing care have resulted in a significant increase in survival rates over recent years<sup>3</sup>; however, the first year of life remains a critical time for infants with complex CHD<sup>1</sup> with mortality after discharge estimated to be 3-5%<sup>4</sup>

# Context of the Study

- This was a longitudinal qualitative feasibility study, within a constructivist paradigm; using Middle Range Transition Theory<sup>7</sup>
- One tertiary children's cardiac centre in the UK
- Participants were parents of infants with complex CHD, who had undergone the first stage of cardiac surgery and were preparing for discharge home

- Overarching research question:

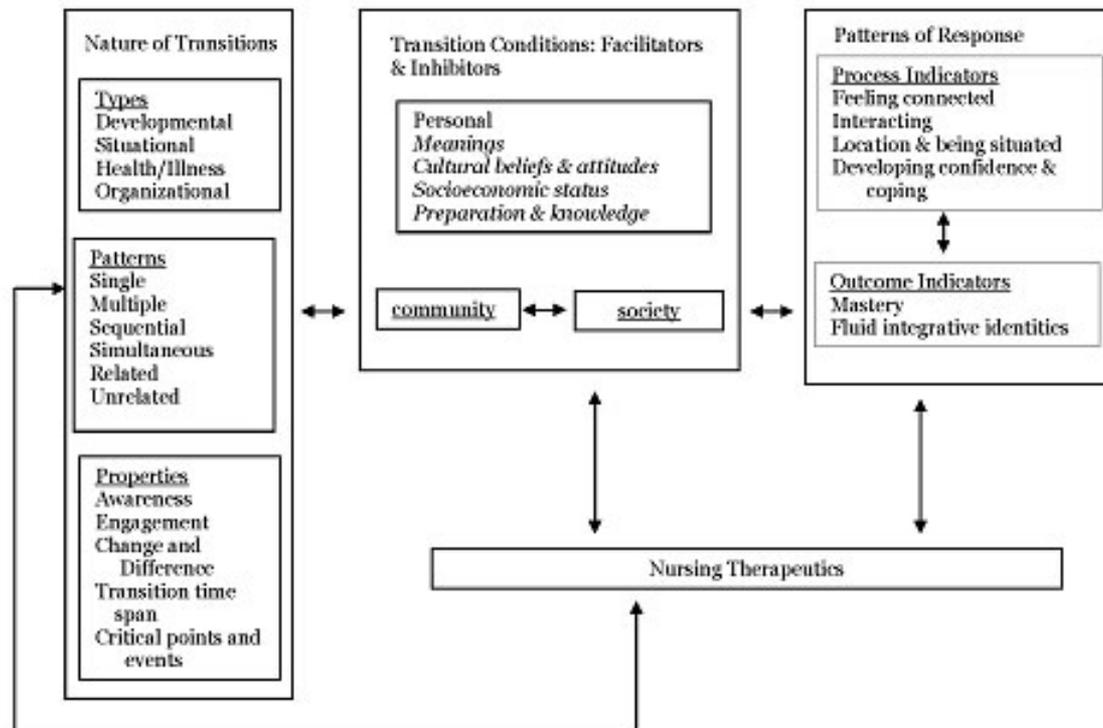
*What are parents' experiences of transitioning from hospital to home with their infant, following first stage cardiac surgery for complex congenital heart disease'*



# Context of the Study

- Eighty infants were screened during the 15month recruitment period, 47 parents were eligible for participation; parents of 13 infants were recruited; parents of 8 infants took part in interviews (8 mothers, 4 fathers), between August 2013 and February 2015
- Parents were asked to participate in self-report tools and semi-structured interviews at four timepoints: before discharge [T0]; two weeks after discharge [T1], eight weeks after discharge [T2] and after stage two surgery [T3]
- Interviews were transcribed verbatim and thematically analysed

# Middle Range Transition Theory (Meleis et al 2000)



# Background - Liminality

Liminality introduced in anthropology in 1909 by Arnold Van Gennep, a concept used to analyse the middle stage in ritual passages; now considered to be a master concept in social and political science<sup>5</sup>

Van Gennep stressed the importance of transitions in any society called 'Rites of Passage', with three phases

- Separation
- Transition
- Incorporation

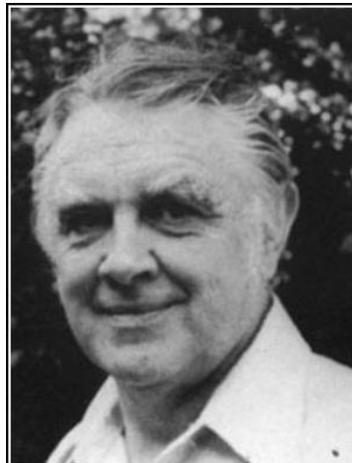


I have tried to assemble here all the ceremonial patterns which accompany a passage from one situation to another or from one cosmic or social world to another. Because of the importance of these transitions, I think it legitimate to single out rites of passage as a special category.

(Arnold van Gennep)

# Background - liminality

- Victor Turner rediscovered Liminality in the 1960s
- Turner suggested that an individual in a liminal space is structurally 'invisible' they are 'no longer classified and not yet classified' and, therefore, are 'betwixt and between' structural classification<sup>6</sup>
- This understanding of liminality opened up opportunities for use of the concept beyond that depicted by Turner, or Van Gennep<sup>5</sup>



The attributes of liminality are necessarily ambiguous... Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention and ceremonial.

— *Victor Turner* —

AZ QUOTES

# Types of liminal experiences<sup>5</sup>

Time	Subject	Individual	Group	Society
<b>Moment</b>		Sudden event affecting one's life (death, divorce, illness)	Graduation; ceremonies	Whole society facing a sudden event, where social distinctions and normal hierarchy disappear
<b>Period</b>		Critical life stages e.g. puberty	e.g. ritual passage to manhood/womanhood	Wars Revolutionary periods
<b>Epoch (or life span duration)</b>		Individuals standing 'outside society', by choice or designated	Religious fraternities, ethnic minorities, social minorities	Prolonged wars, enduring political instability, prolonged intellectual confusion

# Study Findings

Four 'Patterns of Experience' emerged:

- *safety and security*
- *survival*
- ***love and support***<sup>8</sup>
- *mastery*

## ***Love and support***

- A betwixt and between time existed for parents, enabling them to develop, maintain and restore a sense of self and control, such that they were ready to face the hurdle of the transition from hospital to home with their fragile infant.
- Transition across the liminal space was a constraint for some and enabling for others.
- Parents were bounded by physical, emotional and social constraints in terms of their preparedness to go home.

# Transition across the liminal space was a constraint for some:

*“..... we left it so late going home, even though we were discharged like mid-day, but we didn't actually get home until like half past 8” (father, T3)*

*“How do you mean you didn't manage to get home until 8? ...” (interviewer)*

*“clinging on to straws” (mother, T3)*

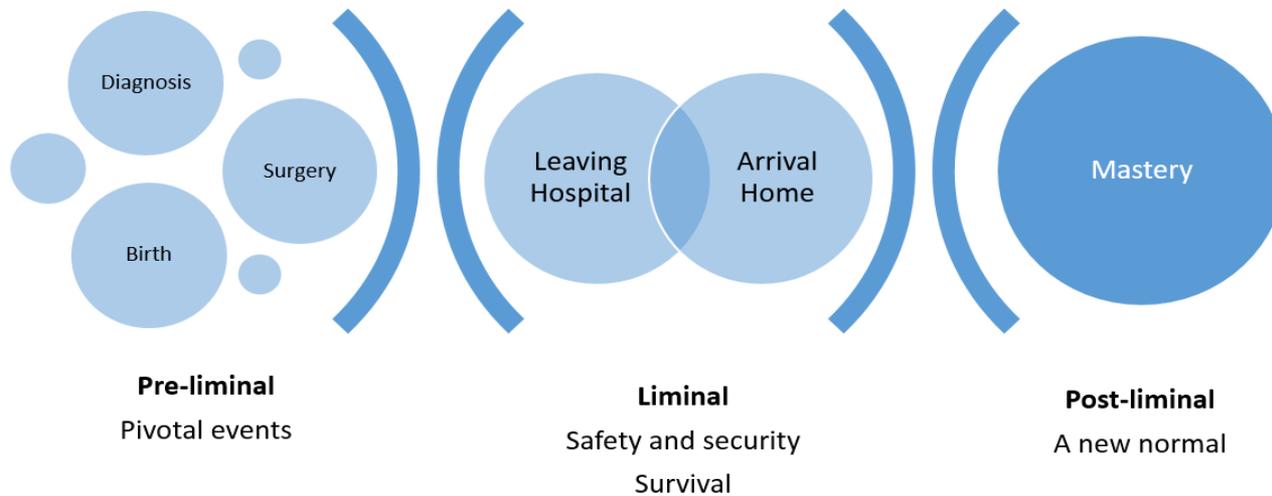
# Conceptual framework

- Developed based on empirical findings, epistemological ontological and methodological assumptions
- Ontologically the framework represents ‘the way things are’ and the ‘nature of reality’
- Epistemologically the framework ‘how things really are’ and ‘how things really work’ in an assumed reality
- Limitations of a 2D model, but aims to represent a dynamic model of transition from hospital to home, incorporating the phenomenon of liminality and the parental experiences of transition through the:
  - pre-liminal phase
  - the liminal phase
  - the post liminal phase

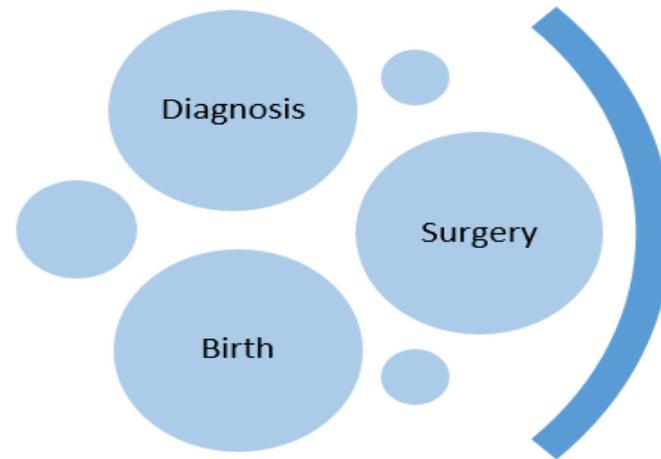
# Types of liminal experiences<sup>5</sup> for cardiac parents and their infants

Time	Subject	Individual	Group	Society
<b>Moment</b>		Sudden event affecting one's life: diagnosis of CHD, birth; surgery; going home; each stage of surgery	Celebrating e.g. at the point of discharge; survival after each stage of surgery	could be national change to cardiac services (following ongoing review for last 10 years)
<b>Period</b>		Critical life stages e.g. birth, pre-operative, peri-operative, post-operative, leaving the ward, stage 1 – stage 2 surgery	e.g. ritual passage after each stage of surgery	Revolutionary periods in terms of advances in cardiac surgery
<b>Epoch (or life span duration)</b>		Individuals standing 'outside society', by choice or designated – 'outside society' as a cardiac parent	Between old and new	

# The rite of passage of transition from hospital to home



# Pre-liminal Phase



**Pre-liminal**  
Pivotal events

# Liminal Phase

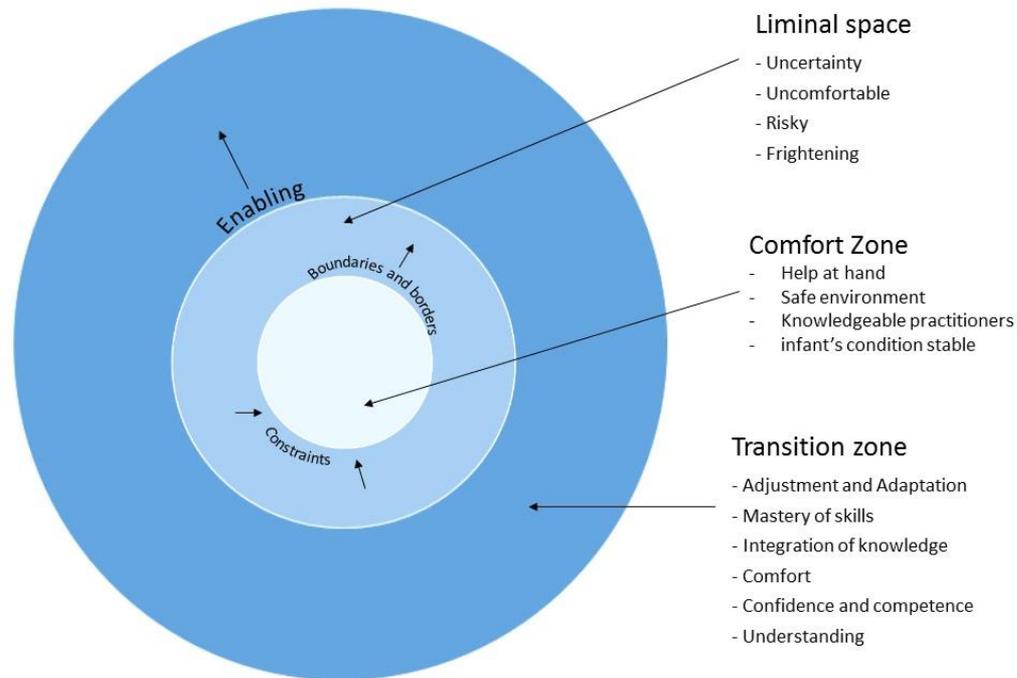


**Liminal**

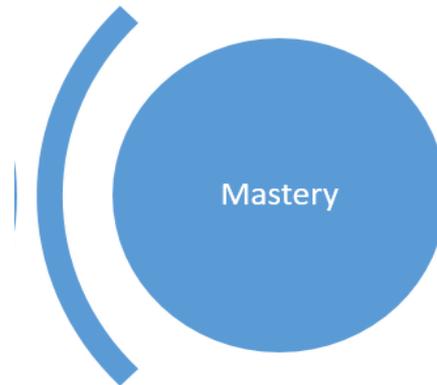
Safety and security

Survival

# Borders, boundaries and liminality

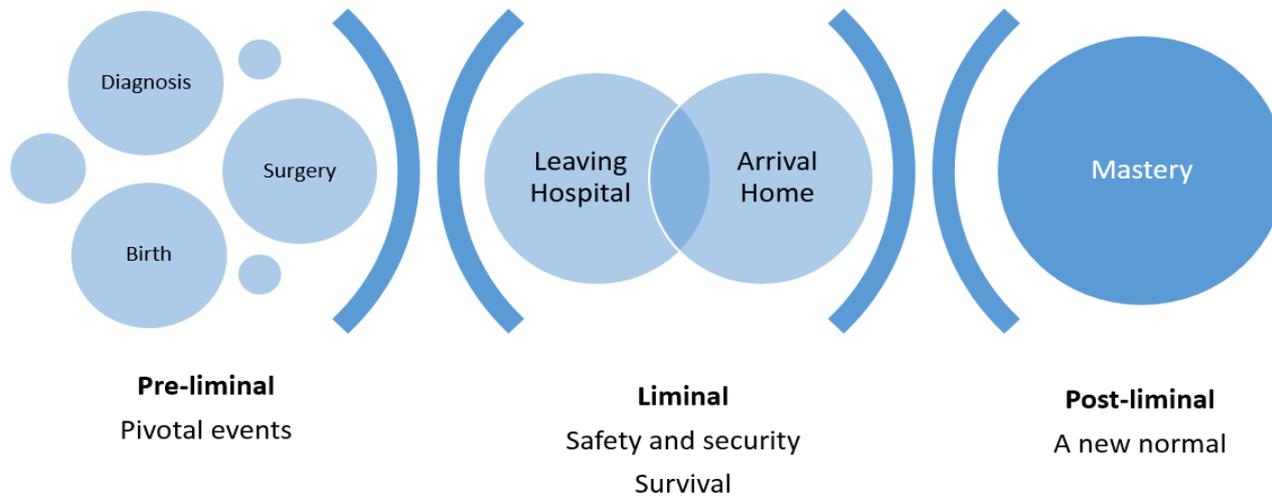


# Post-liminal



**Post-liminal**  
A new normal

# The rite of passage of transition from hospital to home



# Conclusion

- The model represents the parents' experiences of transition through a pre-liminal phase (pivotal events), liminal phase (crossing the threshold of the ward into the outside world) to the post-liminal phase (mastery, developing confidence over time)
- The time frame in achieving the new normal was different and dynamic for each family, but so was the length of time that they were at home with their fragile infant between the first and second stages of surgery
- Key message was the diversity of each family's experience
- Health care professionals need to engage and negotiate with parents to ensure that discharge preparation they receive takes account of their individual differences and preferences and is family centered
- Simplification of the model for practice will enable assessment of each family's needs before discharge planning commences

# Next Steps

Further development of the conceptual framework to demonstrate relevance for practice

Creating a model for HCPs to carefully measure each individual family's needs

Links to wider project around discharge planning



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