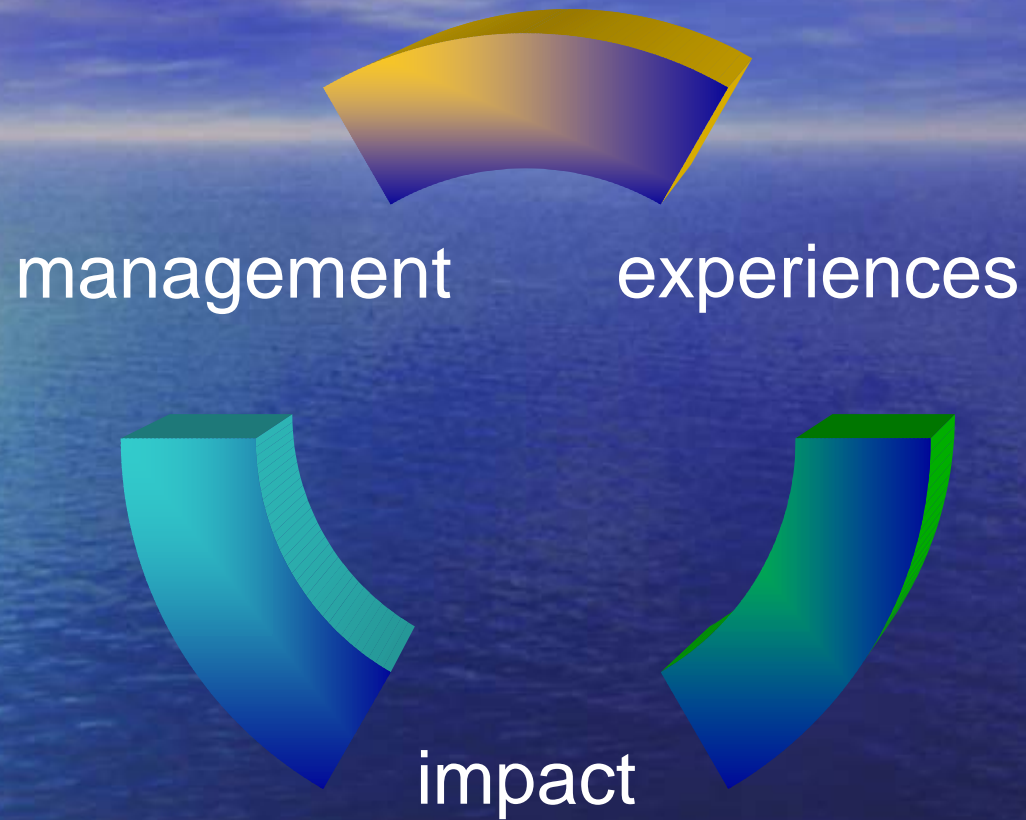


Parental perceptions
of the impact of hospitalisation
of children with special needs
upon the family or whanau

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Overview

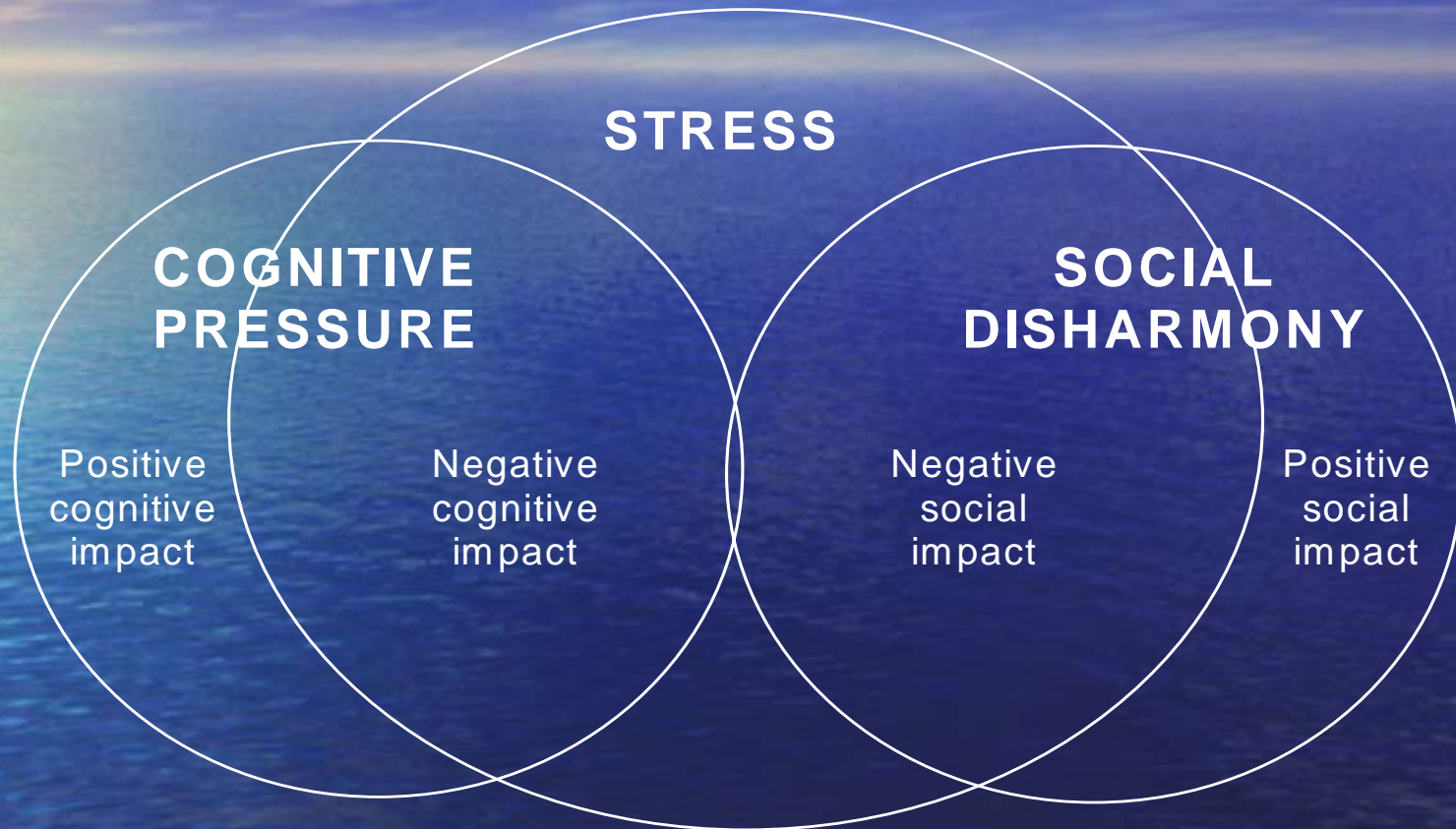


Parents perspectives of the impact of hospitalisation

Outline

- Focus group: 9 parents
- Face to face interviews: 6 parents
- Criteria
 - Child with special needs
 - 5 day+ (consecutive) admission
 - Good understanding of English
 - Willing to participate in a face to face interview

Key areas of impact



Links between the core category stress, and major categories cognitive pressure and social disharmony.

Stress

- shock
- guilt and regret
- powerlessness and frustration
- grief, fear and anxiety
- emotional and physical exhaustion
- health problems

Stress: recurring emotions

"It was very difficult for my son because I had to be pretty mean at times. He would be crying and crying, but I would hold him down with my hands and put the medicine into his mouth. It was very hard and emotionally draining for me to do, but I did it just out of the determination that he had to come out of this... But after I had finished doing that I was emotionally drained because of what I had done to him..."

Cognitive pressure

- pressured learning
- loss of confidence
- personal growth

"I need to keep up with what's happening with my son and what the latest research says about his condition so that I can pose the right question to the doctors and specialists. There's no one else who can put all the information together – I'm the only one who can do that – that's just how it is - it's just a fact. I know I have to get it done..."

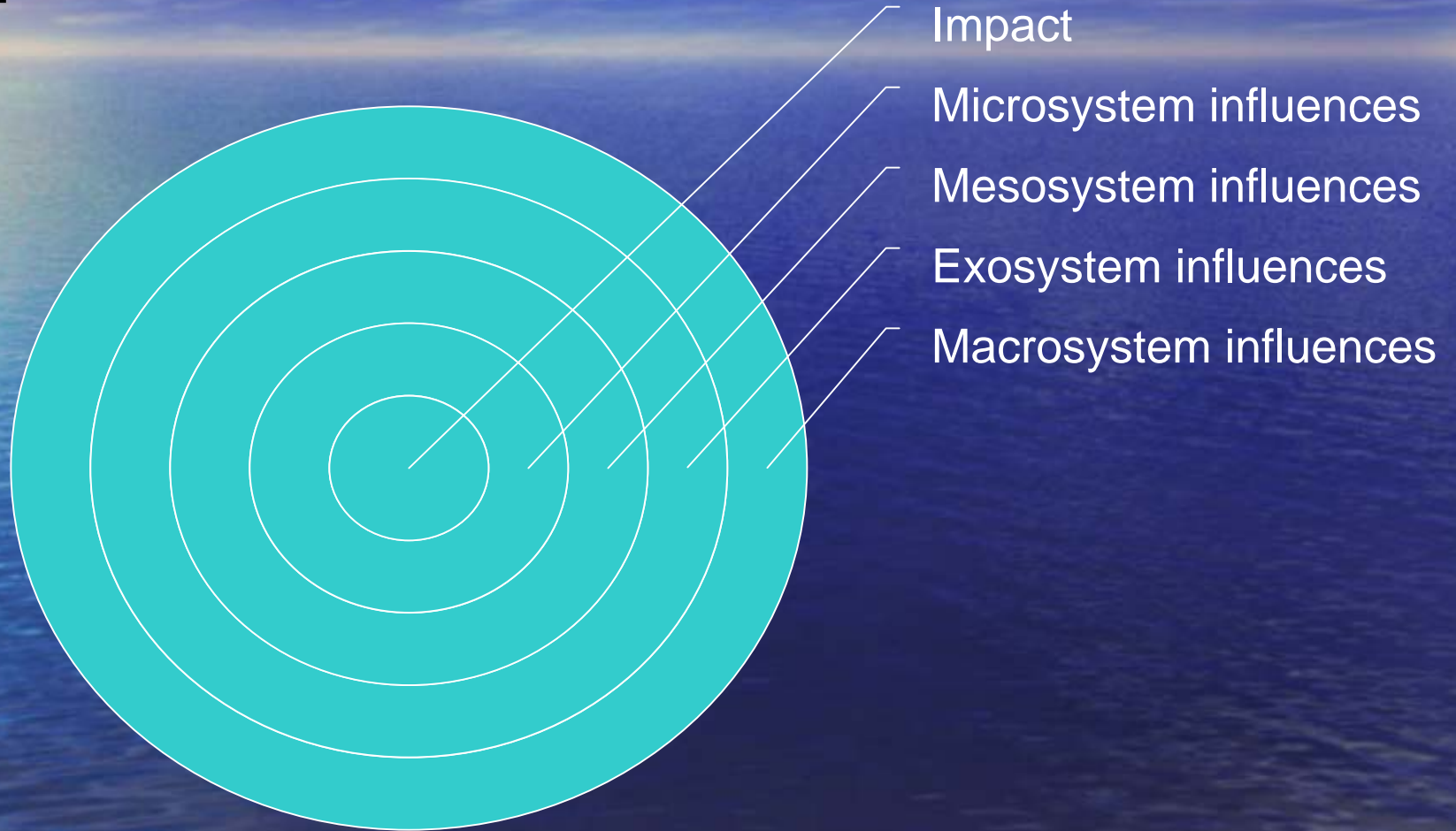
Social disharmony

- disruption to family functioning
- strained relationships
- role change
- isolation
- awareness of true friends

"We'd get 'aggro'. My husband and I would be very irritable. There'd be that resentful feeling about who'd been in hospital the longest with our son and who'd had the longest breaks. That resentment can increase, and at the end of the admission, that can cause problems..."

Systems that influenced the impact of hospitalisation

(Bronfenbrenner, 1995)



Microsystem influences

- perceptions and understandings
- prior hospital experiences
- emotional and behavioural responses
- family characteristics

"If you happen to be in a different hospital with different people and things - you feel uncomfortable. You have new doctors and you're reluctant to ask questions. It's sort of a respect thing..."

Mesosystem influences

- healthcare professional's' attitudes and practice
- values and beliefs of extended families and others
- accessibility of healthcare supports

"I felt they looked at me as if I was a bad parent. That thought can leave you very shaken even with a healthy child let alone a sick one..."

"I had no idea I was entitled to respite care - I ended up being entitled to 24 hours a week, and I didn't know that for 3 months. I could have gone nuts in that 3 months – luckily I didn't, but I could have..."

Exosystem influences

- staffing numbers
- coordination of healthcare services
- government funding of hospital services

"The last time he was in hospital, the nursing shortage was the worst I'd ever seen it and there was even less help to have a break from him – I was ready to jump out the nearest window. He needed to have someone with him all the time. People used to say, 'would you like a break? I'll watch him for a while,' but I haven't been offered that for a long time. That's why I dread going in – once you're there, you just can't get away."

Macrosystem influences

- hospital culture
- societal and cultural beliefs

"If you ask for help, you may start to believe that you are failing as a parent, because you are told by society that you should be able to cope with anything..."

"The main thing is to respect the staff, even if you don't like what they do. It's their home - you are the stranger, so let them do it. Just wait until it is your turn when you go home, then do it your way - then it's your turn to look after your child. It's hard, but it's very important."

Stress



Significant stressors for parents

- loss of control
- divided loyalties
- waning support from employers
- differences in personal beliefs and values
- lack of information
- assumptions by healthcare professionals
- lack of cohesion of healthcare services
- changes in children's behaviour
- lack of awareness of personal needs
- physical and emotional exhaustion

Significant stressors for children with special needs

- visual triggers
- feeling lost or misplaced
- being perceived differently

"Because he looked different and was in a wheelchair, people sometimes thought he was a freak... for a while they tended to lose track of him, and it was all about the illness..."

Significant stressors for siblings

- separation
- unwanted change of caregivers
- differing routines
- peer pressure

"My daughter hides it with some of her friends but if she wants to try and get a sympathy vote she'll say, 'Now don't forget my brother's really chronically ill'..."

Significant stressors for families and whanau

- role change
- feeling scared about the child's fragility
- loss of privacy
- unfulfilled expectations
- adjusting to change in the home environment

"Sometimes it's never going to be back to normal"

Management of stress

- Automatic functioning
 - Survival mode
 - Emotional withdrawal, disassociation
 - Distraction

“We took very much a medical approach even though it was really emotional. ‘Ok, he’s done this, we’ve got over that hurdle’. We didn’t look at tomorrow, because if something went wrong between now and tomorrow, we couldn’t manage that...”

Management of stress

- Accessing support and resources
 - Utilising range of supports
 - Time out
 - Team work
 - Delegation

“Working as a team helped us to cope much better. We knew what we were doing, even in the uncertainty.”

Management of stress

- Regaining control
 - Acquiring new knowledge
 - Reestablishing routines - prioritisation
 - Reassuring others
 - Role change
 - Controlling information
 - Preparation

“We found we became rather secretive – we didn’t divulge information to too many people – we measured our words with other people.”

Management of stress

- Adjustment
 - Acceptance
 - Changed priorities and goals

"[My husband] was ambitious career-wise. But after what we have been through he is not all that interested in career advancement. He says, 'family comes first' – he's changed. What's the point in having more money – we just appreciate having our family... So on one hand we have given up what we wanted, but in another sense we have learned to see things differently..."

Overall impact of hospitalisation

- Changed relationships
- Increased knowledge and skill
- Personal growth
- Changed goals and priorities
- Adjustment to change
- Emotional toll

"It's just such a total disruption to your lives – it's incredible what depth it goes to... The damage it causes is irreparable..."

Summary:

Parents whose children had a range of special needs had many similar experiences

Hospitalisation of children with special needs had a significant and negative long lasting emotional, cognitive and social impact upon families

Recurrent hospitalisations were common for children with special needs – however this did not mean that the negative impact of hospitalisation was reduced for families with each admission

Summary cont'd

- Families used a variety of overt and covert coping strategies to manage their experiences. Problem solving strategies were often used when family members felt they had some control; emotion focussed strategies were used primarily to minimise stress

- Healthcare professionals' practice had an enormous influence upon families' experiences:

thus commitment to, and implementation of,

family centred care is imperative;

the benefits of this approach can be shared by all concerned