FAMILY COMMUNICATION TALKING WITH CHILDREN

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Create change

FACTORS AFFECTING IMPACT ON CHILDREN

Study of 381 families:

- **Children reported more impairment in family function than parents reported (not significant)**
- **Poorer physical status of parent associated with impairment in roles in communication**
- **Depression in the ill parent the most significant factor adversely impacting family function**

Schmitt et al Journal of Clinical Oncology2008;26:5877-5883

PARENTING EXPERIENCES

Survey of 194 self-selected adult oncology outpatients

Functional Assessment of Cancer Therapy - General

Hospital Anxiety and Depression Scale

Distress Thermometer

Parenting efficacy beliefs

Parenting Concerns Questionnaire:

- **Practical impact**
- **Emotional impact**
- **Concerns about co-parent**

ASSOCIATIONS WITH ↓PARENTING EFFICACY

More frequent medical appointments

Receiving intravenous chemotherapy

Poorer physical, social and emotional quality of life

More depressive symptoms

The above also predicted declines in perceptions of co-parent's efficacy in meeting needs of their children

Moore et al Cancer 2015 DOI: 10.1002/cncr.29525

The more unwell the parent is, the worse things are likely to be for the children

PARENT-CHILD INTERACTIONS

Parents are the "gatekeeper" for how and when children learn about the diagnosis of cancer

Even before being told, children sense that something is wrong

Parents lack confidence about talking with their children

Lack of information leads to development of fantasies and misconceptions[1]

In order to "protect" one another from being overwhelmed parents may:

- **Avoid sharing thoughts and feelings[2]**
- **Try to be positive[3]**
- **Focus on giving children information rather than exploring emotional concerns[4]**

[1]Semple et al European Journal of Cancer Care 2013;22:219-231

[2]Hymovich Oncology Nursing Forum 1993;20:1355-1360

[3]Hilton et al Western Journal of Nursing Research 2000;22:428-459

[4]Shands et al Oncology Nursing Forum 2000;27:77-85

THE CONSEQUENCES ARE…..

Children may have significantly higher levels of distress than perceived by their parents[1]

More than one-third of children with a parent with cancer felt their parents did nothing to help them cope[2]

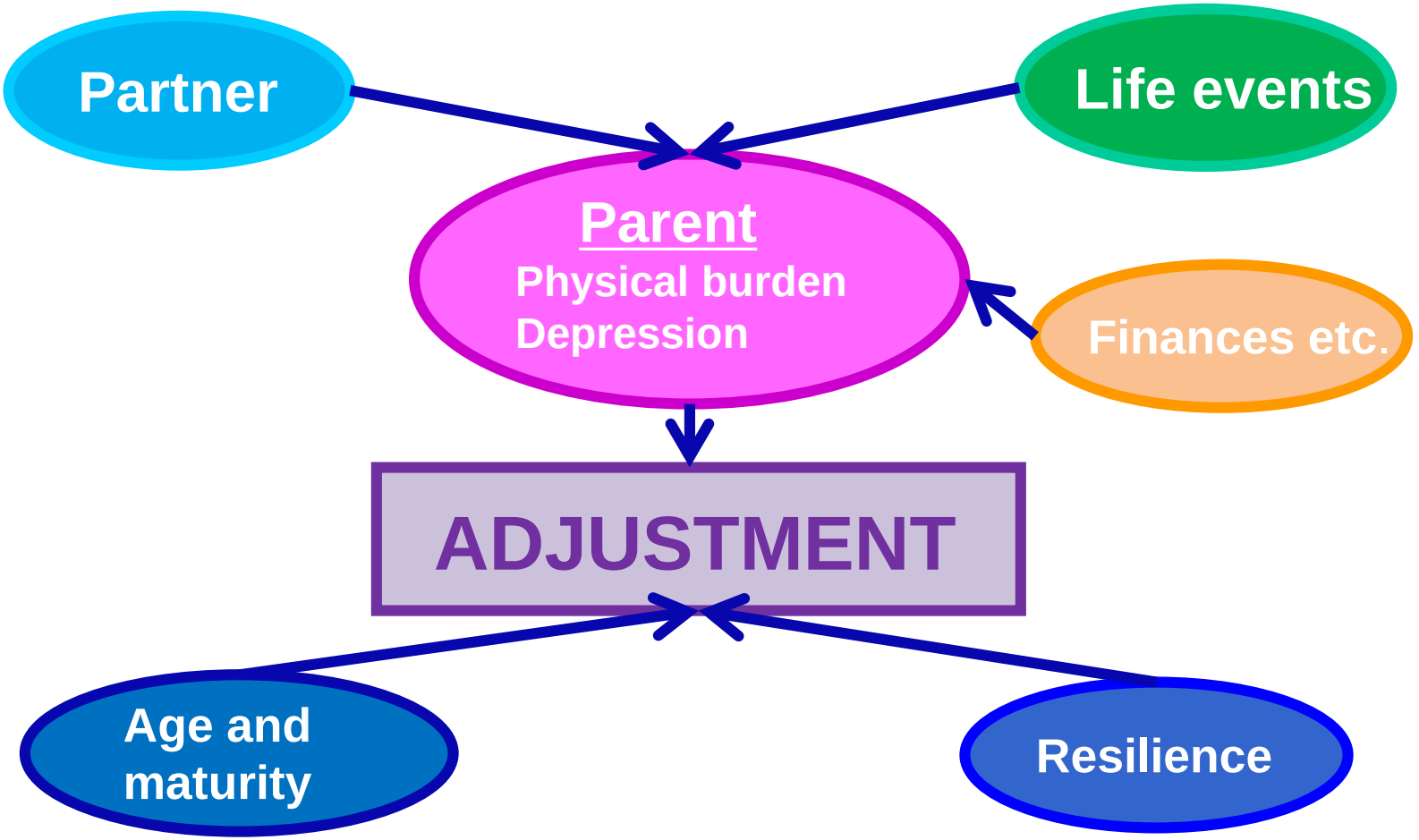
Adolescents (especially girls) are particularly vulnerable[3]

[1]Welch et al Cancer 1996;77:1409-1418

[2]Issel et al Oncology Nursing Forum 1990;17:Suppl 3:5-13

[3]Osborn Psycho-Oncology 2007;16:101-126

CHILDREN'S ADJUSTMENT



Young children (up to about 8 years):

- Egocentric
- Magical thinking
- Authoritarian sense of morality
- Limited capacity to see that things happen by chance
- Anxiety is the most common emotion
  - Fear of abandonment
  - Express distress by behavioural disturbance
  - The child who is “extra good” may be trying to hold things together and “fix” the situation

Need to be aware of lack of understanding that behaviour is an expression of distress

Middle childhood (about 8 to 12 years):

- Need to be accepted by others - importance of social connections
- Being different can be a big issue
- Insensitive comments from other children can be very wounding
- Value being brave and struggle with being distressed
- Limited capacity for abstract thought:
  - Play and physical activity remain important for discharge of tension

Changes in daily life
Mixed feelings about expression of emotional concerns

Adolescents:

- Capacity for abstract thought fluctuates
- Emerging identity/sexuality
- Negotiation of social roles and relationships
- Risk of parentification:
  - Struggle if feel that domestic responsibilities are “dumped” on them
- Social identity matters:
  - Stigma of having a parent who is “different”, “not cool”

Risk of isolation:

- Reluctance to discuss with friends
- Imposition of domestic tasks

Anger and resentment at the injustice of the situation:

- Lack of emotional capacity to integrate powerful emotions: - "*You're ruining my life*"
- Potential for irreversible consequences - pregnancy, sexual assault, STIs, injury in MVA, criminal record, drug overdose

Gap between parental expectations and adolescent reality
Adolescents are not "junior adults"

PRACTICAL APPLICATION

Things that will probably help	Things that probably won't
Talking	Keeping secrets
Maintaining routine	Letting go of structure and rules
Negotiating tasks	Giving orders
Telling children it is not their fault	Telling children to "be good for Mummy"
Encouraging children to participate in sport and normal activities	Expecting children to spend all of their time at home "because time together is precious"
Giving information in stages	Talking about possible outcomes far into the future

Things that will probably help	Things that probably won't
Allowing others to offer support	Feeling that accepting help is weak or will lead to loss of independence
Letting children talk even about difficult things	Rushing to reassure
Encouraging children to work out some problems themselves	Trying to fix everything for them
Letting the school know	Keeping everything private
Maintaining rules and consequences	Letting discipline slip because of guilt
Letting children see that parents are upset sometimes	Always adopting a façade and pretending everything is OK

PARENTS WITH ADVANCED CANCER

CONCERNS ABOUT CHILDREN

"I feel incredibly jealous if I die that someone else will raise my children … cuddle my husband. It burns me up inside… so I don't think about it"

"I watched my father die from lung cancer – will she (daughter) see me rotting and smelling?"

"I don't feel the baby will remember me"

"How many sleeps till you die Mummy?"

Turner et al. Psycho-Oncology 2005;14:396-407

Children with a parent with advanced cancer experience:

- Low self-esteem and self-efficacy[1]
- Difficulties in a number of domains:
  - School (35.5%)
  - Friends (37.8%)
  - Own physical health (39.9%)[2]
- Greater levels of distress than children who have experienced parental death[3]

[1]Siegel et al Journal of the American Academy of Child and Adolescent Psychiatry 1992;31:327-333

[2]Leedman & Meyerowitz Journal of Clinical Psychology in Medical Settings 1999;6:441-461

[3]Christ et al American Journal of Orthopsychiatry 1993;63:417-425

QUESTIONS ABOUT DYING

WHEN A CHILD ASKS THEIR PARENT IF THEY ARE GOING TO DIE

"Well, some people with cancer live for a very long time, and I hope I am one of them. But sometimes people with cancer only live for a short time. That makes me sad – is that something you want to talk about?"

"I am doing everything I can to stay well but there are no guarantees"

"I guess that is possible. But you will always be safe, no matter what"

Turner et al Palliative and Supportive Care 2007:5:135-145

CHILDREN AND BEREAVEMENT

WHAT HAPPENS AFTER PARENTAL DEATH?

Even pre-verbal children can tell that something has happened[1]

By about 5 years most children have some grasp of the difference between a temporary separation and permanence of death[2]

Bereaved children show:

- **High levels of somatic symptoms**
- **Lower self-worth and self-efficacy[3]**

[1]Stuber Western Journal of Medicine 2001;174:187-191

[2]Black British Medical Journal 1998;316:931-933

[3]Worden & Silverman Omega 1996;33:91-102

3-5 years:

- **Intense separation anxiety when separated from primary caregiver**

6-8 years:

- **Love talking about the deceased parent**

9-11 years:

- **Tend to compartmentalise grief e.g. by being very active at school**

12-14 years:

- **Preoccupied with public control of emotions**

15-17 years:

- **Sense of losing part of themselves, grief about the future**
- **Often underestimated by adults**

Christ Cancer Practice 2000;8:72-81

GENDER AND OUTCOMES

Bereaved boys consistently reported to do worse than girls

Fathers more likely to develop a routine through unilateral rules

- **Lack of clarity about expectations**
- **Less awareness of children's needs[1]**

Loss of mother:

- **Before age of 11 associated with greater risk of depression in later life[2]**
- **Associated with poorer sense of well-being and confidence[3]**

"If a mother dies in particular, it is not just the death of a parent but death of a way of life" [4]

[1]*Boerner et al Omega 2001;43:201-216*

[2]*Brown et al British Journal of Psychiatry 1977;130:1-18*

[3]*Saler et al American Journal of Orthopsychiatry 1992;62:504-516*

[4]*Silverman et al American Journal of Orthopsychiatry 1992;62:93-104*

WHAT HELPS?

Parenting qualities:

- **Alert to child's feelings**
- **Helps the child to find language to express feelings**
- **Shows respect for the deceased**
- **Use of humour to modulate pain**
- **Acceptance of child's beliefs about fate of deceased parent**

Nickman et al American Journal of Orthopsychiatry 1998;68:126-134

Protective against depression:

- Being able to talk freely
- Being able to express sorrow
- Being able to ask questions about the dead parent

Saler & Solnick American Journal of Orthopsychiatry 1992;62:504-516

Bereavement is painful but it does not necessarily make children ill

"While the pain of loss may be tempered by time, time does not heal. The bereaved do not recover, in the sense of returning to life as it was before the loss. Rather, they make an accommodation to their new situation, and this accommodation does not have an end product, but changes as the bereaved change over time"

***Silverman Journal of Palliative Medicine 2002;5:449-454* (p.450)**

Health professionals need to resist the temptation to intervene and attempt to "cure" grief

Slavitt Journal of Pain and Symptom Management 2000;20:353-3577

RESILIENCE

Refers to the capacity of the individual to cope and flourish despite adversity - the ability to "bungee jump" through life

Our final destiny is not shaped just by an event, but the *consequences,* often adding together

Protection from adversity does *not* confer resilience

"No child can walk between the raindrops"

Worden

CHARACTERISTICS OF RESILIENT CHILDREN

- ✓ Strong connectedness to at least one adult with unconditional positive regard
- ✓ Perceived area of self-competence e.g. sport, academic
- ✓ Belief that they can control their lives, but able to see what is not in their control
- ✓ More likely to discuss problems at home and be encouraged to face up to difficulties
- ✓ Chores and tasks for the good of the family
- ✓ Seen and respected for who they are
- ✓ Positive school experiences
- ✓ Fewer delinquent peer associations

Note the concept of chain reactions

ROLE OF THE GP

- Acknowledgement of parental grief and sadness
- Information about needs of children
- Importance of communication “even distressing things”
- Early identification of risk factors for the family e.g. parental depression, high disease burden, isolation, avoidance
- Supporting parents to be responsive to their children
- Encouraging optimism that there are things which can be done to make this less dreadful for their child
- It is less about the cancer and more about how it is handled that will influence the child’s future