Karolinska Institutet

Supporting next-of-kin in palliative care with special focus on young adults in bereavement

Background

Being close to someone with incurable cancer in end of life and in bereavement is a difficult experience.

Most people cope well, but
bereavement is associated with increased vulnerability, especially in younger years.

Many young adults lose a parent – little research focuses on this group

Background

Supportive interventions:

- can increase wellbeing
- can facilitate coping
- has to be directed to those in need

Overall aim

The overall aim of my research project is to study the impact of social support given by professionals to next-of-kin of patients with cancer before and after the loss

Substudies

Substudy I

Experiences of support – family members perspective

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Substudy II

Psychosocial health after the loss of a parent to cancer – young adults who participated in a support group

Family members experiences of support - Substudy I

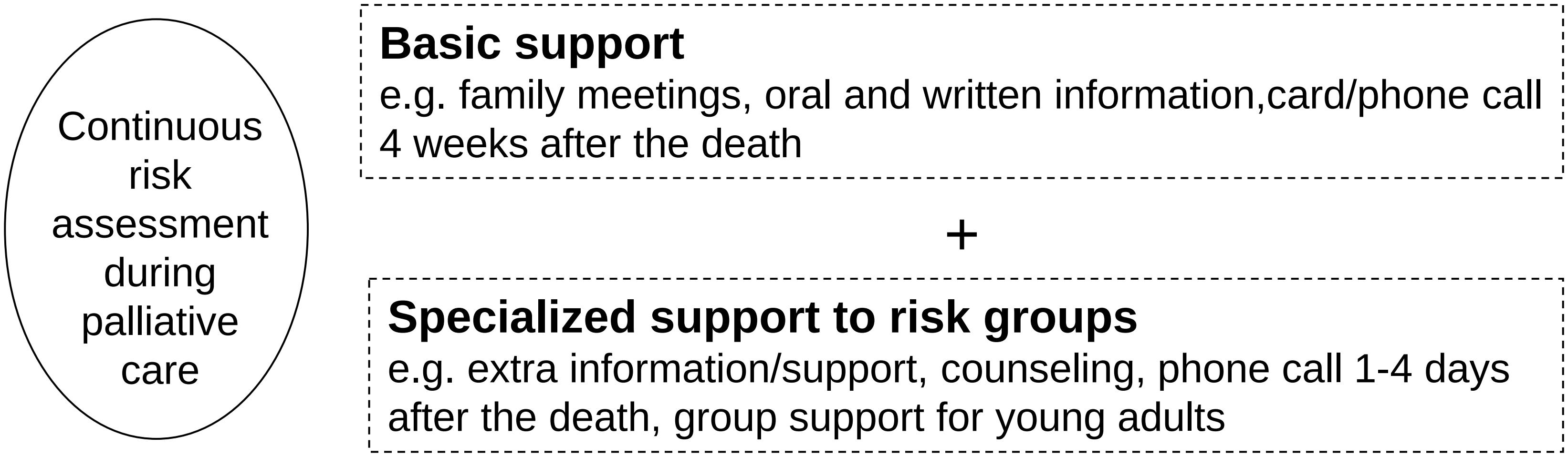
Aim: To explore the emotional consequences of supportive interactions from health care staff given to family members in palliative care

Design: A retrospective qualitative interview study

Context – Substudy I

Care development project

based on identification of risk factors



Continuous risk assessment during palliative care

Basic support
e.g. family meetings, oral and written information,card/phone call 4 weeks after the death

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Specialized support to risk groups
e.g. extra information/support, counseling, phone call 1-4 days after the death, group support for young adults

Risk groups: Children or young adults in family; Sudden, unexpected or difficult dying period; Psychosocial or psychiatric problems

Family members experiences of support - Substudy I

Conlusion: Suppotive interactions with staff and within a home-like environment help to build resiliens if tailored to the family member’s own needs[1]

1. Lundberg, T., et al. (2013). "The perspectives of bereaved family members on their experiences of support in palliative care." Int J Palliat Nurs **19**(6): 282-288.

Aim & Design - Substudy II

Aim: To examine the psychosocial health in young adults who lost a parent in cancer and who participated in a support group

Design: Quantitative, prospective study design

Participants - Substudy II

Young adults, aged 16-28, who lost a parent in cancer and who agreed to participate in a support group

Participants from support groups at palliative care services in:

- Stockholm (where the group was part of the care development
- programme in substudy I)
- Gothenburg
- Uppsala

Quantitative data collection – Substudy II

Questionnaires at 3 occasions up to 15 months after the loss

Data collection

	Questionnaire 1	Questionnaire 2	Questionnaire 3
Support group: Parent's death	(start of group)	(end of group)	(6 months after end of group)
	3-6 months after the loss	6-9 months after the loss	12-15 months after the loss

Questionnaires – Substudy II

Comprehensive questionnaires – questions about:

- Age, gender, work, living conditions
- Circumstances around the loss
- Quality of relationships with parents and friends
- The grief
- Support

Free comments at the end of the questionnaire

Questionnaires – Substudy II

Questionnaire 1 contains scales 1-5, questionnaire 2 & 3 also contains scale 6.

1. Young Person’s Grief Perspective Scale
2. Hospital Anxiety and Depression Scale – HADS
3. Rosenberg Self Esteem Scale – RSS
4. Feelings of loneliness, ability to concentrate, attendance at studies/work, belief in future meaning (Self assessment on a 7-graded numeric scale)
5. Life Satisfaction Checklist (LiSat -11)
6. Posttraumatic Growth Inventory – PTGI

Result - Substudy II

Number of responses (women/men)

Participants	Questionnaire 1	Questionnaire 2	Questionnarie 3	Questionnaire 1-3
88 (71/17)	86 (72/14)	72 (61/11)	67 (54/13)	63 (51/12)

Publication I - Substudy II

Publication I: Psychosocial health of young adults who lost a parent to cancer

Aim: To provide a comprehensive description of circumstances around the loss and psychosocial health among young adults who have lost a parent to cancer

Design: Cross-sectional

Analysis: Descriptive analysis of baseline data

Result – Characteristics

- 86 young adults, 16-28 years (Mdn 23) answered on average 5-8 months after the loss
- Women 85%. Men 15%.
- 95% were born in Sweden
- 28% lived alone, 33% with their partner, 35% with the still living parent
- All had previously lived with the deceased parent, 59% did when the parent died
- 58% had a partner
- 89% were working and/or studying

Result – Loss-oriented variables

- 58% had lost their mother, 42% their father

- 89% had a good relation to the deceased parent

- 19% did not know at all or knew only a few hours before about the impending death

- 26% had talked about important things the last week
- 25% had not since they did not understand that the end was near

- To 23% the death was unexpected
- To 46% the death was expected, but not at that very moment

Result – Restoration-oriented variables

- 59% had a good relation to the still living parent

- 73% had shared their grief with family or relatives
- 10% had not shared their grief with anyone

- 81% had received support from family and friends
- 58% had received support from a professional
- 16% had not received support at all, of which 10% would have wanted support

Result – Psychosocial health

Rosenberg Self-esteem Scale	85	
Mdn (q1-q3)		10 (7,5-14,5)
Low self-esteem, n (%)		64 (75)
Normal self-esteem, n (%)		21 (25)
High self-esteem, n (%)		0 (0)

Total score range 0-30.
<15 indicates low self-esteem, 15-25 Normal Self-Esteem,
25-30 High Self-Esteem

Result – Psychosocial health

Hospital Anxiety and Depression Scale		
Anxiety, Mdn (q1-q3)	83	10 (7-13)
Normal, n (%)		23 (28)
Mild, n (%)		25 (30)
Moderate to severe, n(%)		35 (42)
Depression, Mdn (q1-q3)	81	6 (3-8)
Normal, n (%)		56 (69)
Mild, n (%)		21 (26)
Moderate to severe, n(%)		4 (5)

Total score range is 0-21 for each subscale.
Range <8 normal, 8-10 mild and >10 moderate to severe anxiety or depression

Result – Psychosocial health

Life Satisfaction Checklist, n (%)		Satisfied
Global life (life as a whole)	85	29 (34)
Work	84	20 (24)
Economy	85	25 (29)
Leisure	86	35 (41)
Contacts with friends	86	40 (47)
Sexual life	82	21 (26)
Family	84	30 (36)
Partner relation (those with partner)	48	28 (58)
Physical	86	27 (31)
Psychological	85	14 (16)

Resultat – Psychosocial health

Young Person’s Grief Perspective Scale, n(%)	83	
Vulnerability in grief, Mdn (q1-q3)		17 (14-21)
Severe vulnerability, n (%)		4 (5)
High vulnerability, n (%)		17 (20)
Low vulnerability, n (%)		62 (75)

Total score range 0-36.

Score >20 suggests low, 21-23 high and <24 severe vulnerability.

Score range per domain: 0-12.

Conclusion

- Young adults experience poor psychosocial health after the loss of a parent
- The increased knowledge provides an important basis that informs health care services who meets and supports young adults during and after end-of-life of their parent.

Thank you for listening!