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It isn't just passed: a salutogenic perspective on bereavement care after stillbirth

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Abstract

Mothers and fathers of perinatal deceased babies usually get professional care in most European hospitals. In spite of the availability of care, many parents feel left alone with their experience. Mothers report not being taken seriously in their needs and lacking appropriate information. What are the reasons for this misfit? Why seem professionals, although present, not to be close enough to the mothers' needs? Based on the theory of Salutogenesis by Aaron Antonovsky and on evidence about mourning processes after the loss of a child and grounded on clinical practice the authors develop a health oriented approach in bereavement care for couples who have experienced the loss of their baby.

Introduction

Perinatal child death occurs relatively seldom in rich industrial countries. Accordingly, death rates, when measured on the total births with 0.2 – 0.5% are relatively low in the German-speaking countries of Europe However, for instance of 430 perinatal deceased children in Austria [1], 3907 in Germany [2] and 596 in Switzerland [3], every year many more people are affected: the perinatal deceased babies leave behind mothers, fathers, siblings and grandparents. If we take these much larger numbers of those affected into account, then the picture of the "seldom" phenomenon of perinatal child death is relativized. Not relativized is the existential and drastic affectedness of the bereaved. Therefore, it should be natural that they meet a counselling system that accompanies them well in a medical, psychological, social and spiritual manner. That this is not the case is shown by current global sensitising actions [4] as well as by first systematic researches on quality of counselling after stillbirth in Switzerland [5].

Background

Experts in midwifery state that the counselling of affected parents is good or very good. The affected mothers see this differently (Figure 1) [5]. In comparison with mothers with children who are born alive, they feel they have been scarcely informed concerning their own health and some of them state they had not been well provided with medical care.

Women who have experienced a perinatal child death feel that their needs have not been as well taken into account and have been consulted much less in their decision on care than women with live births. Much more, they miss good emotional counselling after birth and do not feel that they have been sufficiently included in decisions that concern themselves or the dead child. The same applies to their role as parents that is more complicated with a child that is born dead than with the birth of a living child. The chances of adequate support in this area are little higher than 50%.

These findings are surprising, especially in view of the background of the positive evaluated presence of the professional after a perinatal child death. Many mothers report that in the first month after the birth there was always someone there for them when they wanted to discuss fears or worries [5]. Yet the mothers felt that they were often not taken seriously in their needs, received too little information and were left alone in their experience.

Models of "normal" grieving process

The way in which a perinatal loss experience affects concerned mothers depends decisively on how successfully the couple and the social environment are able to integrate the experience. For a long time, assumptions and models defined the ideal way of "loss processing", that included a structured coping with bereavement in a timed sequence of defined phases [6]. These phase models often implicitly defined how "correct" mourning is to be carried out. The realisation and acceptance of the loss is followed by the coping with the loss, i.e. the actual mourning that is linked with the loosening of the emotional bond. Only then, as a third part, is the resumption of the emotional life or the entrance of new bonds possible.

However, empirical studies describe a different form of the "natural" mourning process after the loss of a child. This does not run in sequential, separate, steps but in **individual dynamics of the change from grief and normality, coping and prevention, learning and denial, crying and laughing** [7].

However, if professionals in the counselling of couples and mothers after the loss of a child orient themselves on structural models of coping with bereavement, then it can be assumed that they are present, helpful and empathetic but fail in meeting the needs of the affected parents

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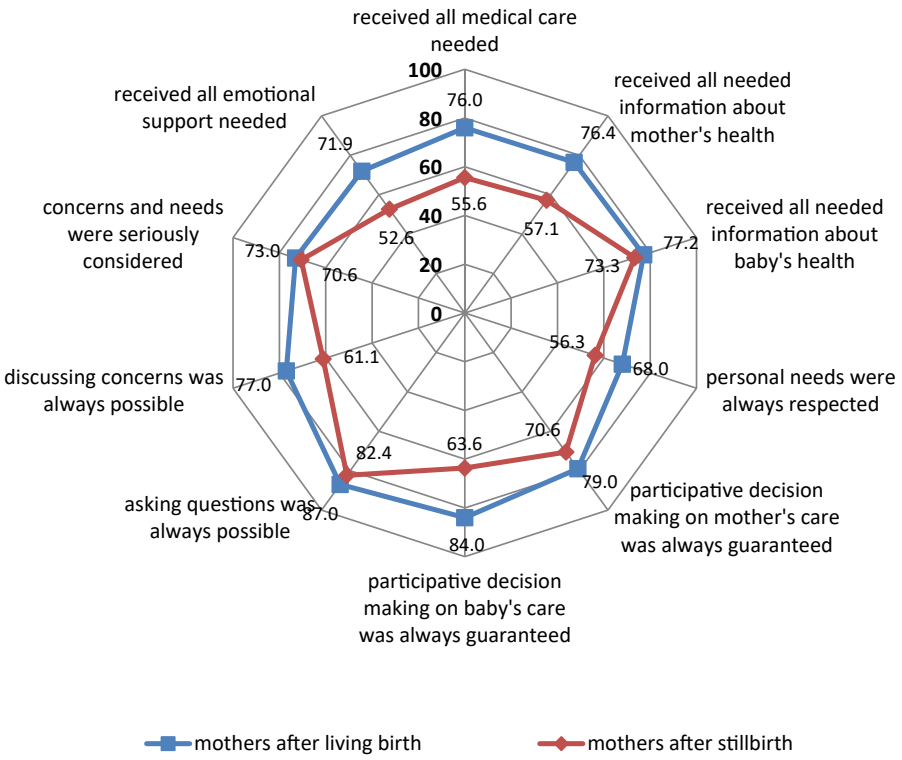

Figure 1. Perceived quality of postnatal care 1-30 days after birth: satisfaction of mothers after live birth (N=1055) and stillbirth (Meier Magistretti et al, 2014, p.37)

because they are guided by normative (grief) concepts. These do not necessarily correspond to the subjective experience of the affected mothers, fathers and families.

Salutogenic perspectives of the perinatal child death

Professionals as well as affected persons require **models for orientation**: ideally, these should apply to the "natural" course of grieving processes after the loss of a child. In order to develop such models, knowledge of grieving processes is as important as answering questions concerning factors that support these processes.

Concepts from the theory of Salutogenesis are a central part in coping with perinatal child death and decisive for long-term psychological and physical health of mothers and fathers [8]. As the name states, the Theory of Salutogenesis according to Aaron Antonovsky (1987) focuses the origins of health: this is in contrast to pathogenesis, which researches causes of illness.

When we view mourning and mourning processes as non-pathological processes, then it is possible to perceive them from a health-oriented perspective: "How can we support 'natural' mourning processes?"

Here two concepts from Salutogenesis provide a first answer:

- The health-illness continuum
- The sense of coherence

Health and grief in the continuum

The concept of the health-illness continuum states that:health and illness are not fundamentally contrary stable conditions, but that health is a process on an continuum between the poles of health-ease and health-disease.

In analogy to the process of health we can refer to grief-processes after a perinatal child death. "Grief" and "normality" are much rather poles between which the affected persons move after the loss of a child and that do not exclude each other.

Accordingly, grief is no pointed perception and experience but is subjected to procedural grappling with the damaging and with pain. Znoj points out that grief is not a pathological condition but a dealing with a painful and debilitating condition after parting and loss [9]. Correspondingly, the grief handling process oscillates: phases of despair and grief change to moments of banal normality, to joy, laughter and the desire for happiness.

Sense of coherence in the grieving process

The second concept that is proposed here as a model of grief counselling is the **sense of coherence**. This is understood to be a persistent but dynamic basic trust in life and the inherent capacity to cope with it. The sense of coherence consists of three components:

- **Comprehensibility**: this means the trust that events and tasks in life are basically understandable, that the tasks to be faced can be foreseen to a certain extent and that it is possible to cognitively integrate events and challenges.
- **Manageability**: this includes the conviction that tasks and challenges of life can be mastered, that resources for mastering them are available and that in the case of lacking own resources, help can be found in the outside world.
- **Meaningfulness**: this means that it is worthwhile to take on tasks and challenges of life and to invest effort in them [10].

In summary, the sense of coherence is a measurable orientation, which makes it possible to activate available resources for the maintenance of health and wellbeing, to protect oneself from health stresses, to overcome stressors and to achieve a positive quality of life [11].

Previous research on the sense of coherence showed positive correlations between the sense of coherence and lifelong psychological and physiological health. In addition, there is clear evidence of linkages between parental sense of coherence and the capacity of the parents to overcome difficult life events and trauma as well as difficult situations in connection with their children [7, 12-15]. A strong sense of coherence also supports the coping with a perinatal child death [8] (Figure 2).

The "natural" course of grief

Every process of grief requests an individual approach. It has been found when working with grieving parents that refusing to categorisations and structured handlingalong predefined phases of grief allows the process of bereavement more flexibility and leeway.

In the context of coping with grief after a perinatal child death, the parents pass through a challenging time both individually and together as a couple. At the start of mourning, this is accompanied by intensive pain that changes in the course of time, develops, becomes less dominant and can suddenly reappear with great intensity. Questions arise: "How do I feel as a woman and man after the death of our child?" – "Have we still become parents?"

Partnership conflicts

In a relationship, the individual and gender-specific differences in mourning sometimes lead to partnership conflicts and are mirrored in the couple-dynamics. The couple that has spent nine months preparing for the arrival of the child is confronted with a large intensity of grief, shame, guilt and injury.

Women mention that they often feel left alone in their grief. They miss the mutual weeping with the partner, the mutual speaking, the exchange of the birth experience and tender affection. This **"Feeling of being left alone"** can sometimes lead women to believe that the partner, the father, does not really love the deceased child.

Parallel to this, partners report they feel responsible for easing the burden in daily life, organising the household and providing care for the dead baby's siblings. Therefore, men tend to aim his actions to "free" the woman as quickly as possible from her grief. In this, the mourning father torn between to two dilemmas: on the one hand's side, he assumes to be able to relieve the woman from her grief and to be responsible for this, on the other hand's side, he might wish to allow himself his own grief. Znoj (2012), also describes the influence of western cultures that make it more difficult for men to be allowed to express and show their feelings [9]. In this conflicting tensions, fathers often become silent and may descend into a form of exhaustion as a result of suppressed emotions [16].

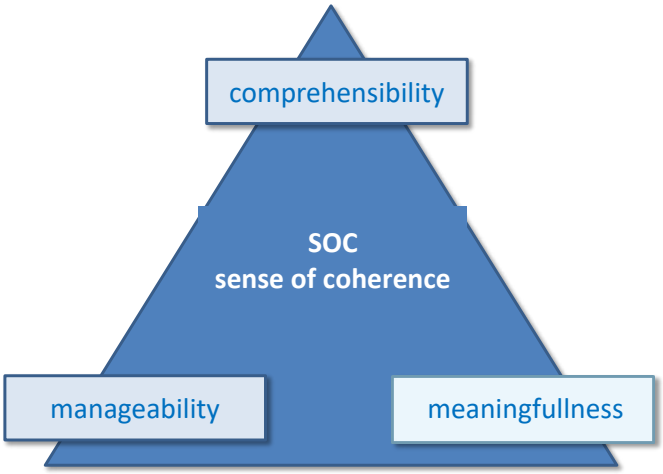

Figure 2. The dimensions of the Sense of Coherence [5]

In this debilitating process it is good to show understanding and to explain that the different ways of mourning are normal. The many-sided and multi-dimensional physiologic course of mourning should be pointed out. This acquired knowledge and the resulting mutual understanding between father and mother lead to the end of the conflict of who is mourning more about the child or who loves it more.

Agonizing questions

The bewilderment and the desire to make the event a non-event, the wish to awake from the "bad" dream are feelings that those affected experience intensively. At this moment questions arise that are expressions of powerlessness and hopelessness: "What has happened, why me?" - "What should I have done differently?" –"should I have noticed in a way that my baby is not well, that is has left?" – "Was the decrease of, or were the too intensive child movements a sign of the approaching death already"? – "Shouldn't I have climbed a mountain yesterday?" – "Were the annoyances of the daily challenges to damaging for my child?" Accordingly, Heazell and colleagues report that parents often are convinced that they have not protected the baby sufficiently [16].

To go on living without the child seems an inconceivable perspective. The pain and hopelessness are difficult to bear. It is difficult to cope with the sense of powerlessness and with the feeling that everything is falling upon them like an avalanche and the structure or the dream of a healthy and happy family are crumbling. In this moment, parents are overwhelmed by a flood of emotions, they feel as if they were merely functioning, actually being under the control of outside forces and they report a state of mind as if a fog had formed around their consciousness. The wish is to close the eyes and not to take anything as being true, to wish to reverse it and to even wish for one's own death [9].

Burdening decisions

Additionally, difficult decisions have to be taken: "Is an autopsy to be carried out? What kind of funeral do we want for our child? Should the siblings, the relatives attend? Could attending the funeral be or damaging for the siblings? What do my other children need for coping with their grief? What costs must be taken on?" The discussions of Downe [17] confirm that the mourning and the affectedness is not restricted only to the parents but also extends to the baby's and to the parents' siblings, the grandparents and friends.

Wish for normality

In parallel and contemporarily, affected parents experience a deep wish for normality: they wish to do things that seem banal, they wish to laugh, to have pleasure in a good event. But they often doubt asking: "Am I allowed to do this?", "Is my grief too weak, have I not loved my child enough?" – "How will my surroundings react if I laugh?" It is difficult to master the change of these intense feelings and their

multitude, which act subjectively like a wave movement between joy and sorrow. These emotions cannot be called up or controlled. They appear suddenly and unprepared – like laughter or like tears.

Need for support

To accept these feelings and to be able to understand them as part of one's own processes helps in building up security and stability in the middle of the swinging moods. In addition, many parents have a wish for continued support in coping with feelings of shame, guilt, helplessness, hopelessness, despair and anger. A successful manageability aims at integrating the experience in the individual's personal life story. In addition to the dimensions of understanding and manageability, there is the third component of the sense of coherence: the sense of meaningfulness. The question of meaningfulness must be viewed very carefully. Because not too seldom after a perinatal child death, parents are confronted with statements such as, "Maybe everything has a meaning," or "It's God's wish." These sayings lead to further damage and the feeling that one is not being taken seriously. When we talk of meaningfulness here, it means the comprehensive individual development in the process of the grieving couple, how quickly one discovers one's own answers. These answers can only be given by those affected. Professionals here take on an advising position, fostering the parent's process of creating comprehensibility, manageability and meaningfulness .

How can professionals be of help?

Starting with the described "natural" process of mourning and the clinical experience, there is the question of how a **Salutogenic orientation of midwives can be used in practice**. Two factors are of importance: the turning away from standardised assumptions of "correct" mourning processes and the strengthening of the sense of coherence as heuristic in the accompaniment of those affected after a perinatal child death.

Turning away from standardised means that every couple and every death of a baby is seen and accompanied in the respective own individuality and that midwives (and also all other counselling professionals) remember that they are dealing with a process that oscillates and is dynamic and that cannot be dealt with by means of fixed "treatment schemes".

The sense of coherence, as **dynamic orientation**, can supersede the static phase model (possibly inadequately) and can support professionals as well as those affected to find their way through the strongly emotional different processes.

Medical and psychological information must be used for the perinatal child death but also for the reaction of the affected couple and their mourning process in such a way that understanding can be achieved.

This occurs in that professionals focus on perception instead of (quick) interventions and not only impart information but that in an interaction of information and verification together with the parents they communicate in such a way that mothers and fathers can obtain orientation and security. In this way couples are encouraged to use their own resources and to overcome their speechlessness. They can learn to experience, communicate and handle the intensity of their emotions.

The heuristics of the dimension of the sense of coherence finally supports professionals as well as those affected not to give up, to face the dense, intensive and multitudinous challenges and to permit their own actions and the own subjective meaning – the deep mourning as also a visit to a hairdresser or a drive to the car wash.

Successful support, this is shown by the statements of the women themselves, is to be admired.

"Our midwife visited us daily for 2 to 2 ½ hours. She helped me with breast engorgement (I wanted the milk to come naturally and also to go away again). She was there when the undertaker came to the fetch our daughter from the house, she was there at the parting ceremony; we had long conversations… She was an extremely important contact person for us. We felt supported from the start, looked after and understood. Without her we would not have got over things as well."

References

1. Statistik Austria. http://wwwstatistikh
2. Statistiches Bundesamt 2016: Available: http://www.gbe-bund.de/oowa921-install/serviet/oowa/aw92/WS0100
3. BEVNAT (2016) Bundamt für Statistik. available: http://www.bfs.admin.ch/bfs/portal/de/index/themen/01/06blank/key/02/01.html
4. Flenady V, Wojcieszek AM, Middleton P, Ellwood D, Erwich JJ, et al. (2016) Stillbirths: recall tom action in high income countries. *Lancet* 387: 691-702. [Crossref]
5. Meier Magistretti C, Rabhi-Sidler S, Auerbach S, Luyben A, Varga I. Wenn die Geburt der Tod ist. Nachgeburtliche Betreuung der perinatalem Kindstod. Eine Studie zu postnatal care im Rahmen der COST-Aktion IS907 "Childbirth, Cultures, Concerns and Consequences" . Luzern HSLU-SA 2014.
6. Kast V. Trauern, Phasen und Chancen des psychischen Prozesses. Stuttgart (1990) 2008.
7. Hedov G, Annerén G, Wikblad K. Swedish parents of children with Down's syndrome. Parental stress and sense of coherence in relation to employment rate and time spent in childcare. *Scand J Caring Sci* 2002; 16: 424-430. [Crossref]
8. Uren T, Wastell C (2002) Attachment and meaning-making in perinatal bereavement. Death stud 26: 279-308. [Crossref]
9. Znoj H. Trauer und Trauerbewältigung. Psychologische Konzepte im Wandel. 1st issue KohlhammerVerlag 2012.
10. Antonovshy A (1987) Unravelling the mystery of health: how people manage stress and stay well. Jossey-Bass Social and Behavioral Science Series.
11. Lindström B, Erikson M. The Hitchhiker's Guide to Salutogenesis. Salutogenetic pathways to health promotion. Helsinki Folkhälsan 2010.
12. Einav M, Levi U, Margalit M (2012) Mothers' coping and hope in early intervention. *Eur J Special Needs Edu* 27: 265-279.
13. Pozo Cabanillas P, Sarria Sanchez E, Mendez Zaballos L (2016) Stress in mothers of individuals with autistic spectrum disorders. Psicothema 18: 342-347. [Crossref]
14. Schmitt F, Santalahti P, Saarelainen S, Savonlahti E, Romer G, et al. (2008) Cancer families with children: factors associated with family functioning – a comparative study in Finland. Psychooncology 17: 363-372. [Crossref]
15. Svavardottir EK, McCubbin MA. Kane JH (2000) Well-being of parents of young children with asthma. Res Nurs Health 23: 346-358. [Crossref]
16. Heazell AEP, Siassakos D, Blencowe H (2016) Ending preventable stillbirths 3. Stillbirths: economic and psychological consequences. *Lancet* 18: 1-13.
17. Downe S, Schmidt ER, Kingdon C, Heazell (2013) Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study. *BMJ Open* 3: 1-10.