ECP-Akademie

GD Bildung und Kultur
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Eliminate grief barriers

Thoughts and tools taken from the EU-Partnership Project „Dying and Death in Europe“

Death has vanished from our modern society. According to a German report in 2009, 80 % of all people wanted to have a dignified death surrounded by their family. The reality is less than 20%. Most people dy in hospitals or care homes. Up until now only every fifth person can get a place in a hospice and this places are reserved for certain illnesses. At least everyone should be able to rely on being cared for on the last journey, whether at home, in care centers, by the family, personal assistants, either on a voluntary basis or professionals.

Being looked after at home must be well organised and affordable. Political conditions, to support relatives in managing the care, must be available. The demand for getting a new culture of dying is not enough.
Due to the successful work done by the hospice movement, society has become more aware of this topic, but is being led in the opposite direction. Dying people used to be abandoned and even their relatives were left to their own devices. In the last view years there have been more offers of help.

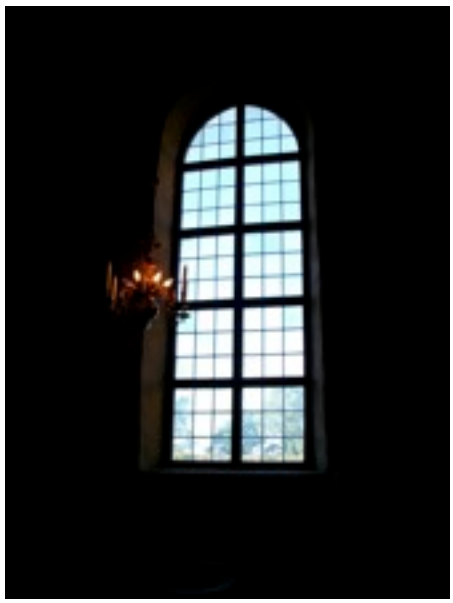
That is good and helpful but one must not forget, that this direction is going towards a new professionalism of making money out of dying. More and more voluntary helpers are being trained to close the financial gap to ensure continuous care.
The dependence on volunteers reveals the need for easy useable tools to deal with psycho-social aspects. A special concern is the process of saying farewell and supporting the bereavement process.

People are confronted by their feelings in loss and death. It is similar to a birth. Even if you have been prepared for nine months you are just as overwhelmed by the feeling of happiness as you are shoked after a loss and grief hits you with its severity. Even if you are prepared in advance and you accept death as a release, it

still hits you when a loved one passes away. Sometimes it is like being steamrollered.
People talk about one year of mourning. If it lasts longer, it is seen as pathological mourning, depression or other psychosomatic illnesses, which are explained as unresolved bereavement.

Thinking about this time of suffering and the economical loss for the society, the importance of supporting the bereavement process becomes obvious. A bereavement process actually starts when a terminal diagnoses has been given and you imagine not having much time left together. Many people avoid the truth and try to hide the pain by rejecting their feelings. Blind and useless activities are also seen as false considerateness.

In the EU-Project Dying and Death in Europe, Josep Soler from Spain talked about a silent conspiracy in his culture. Spain has got the highest EU average of old people and at the same time the highest rate in plastic surgery.



There is probably a social tendency to make a secret out of death. This means that valuable time is not used to appreciate each other to show love and to say goodbye. The chance to solve problems, to fulfil wishes and arrange the last Will has been taken away. An easy bereavement process has been lost. The terminal patient dies in solitude. Conciliation has no chance. Many questions are left open and feelings of guilt make the process more difficult.

Even father Dr. Piotr Krakowiak the director of the Polish hospice foundation is against the white lies spread by the Polish Catholic society. He reported that patients feel the end is coming sooner or later and respond, by becoming angry or disappointed that they have been lied to by their relatives. Very often this is followed by depression and fear which again is treated with medication. A loving goodbye with forgiveness and gratefulness becomes more difficult or impossible

It is thought that most people in Europe die in a more or less distinct atmosphere of dishonesty and unspoken truth. Systematically three factors work negatively together.

1. the medical timescale:
Because everyone wants to believe in recovery, or does as if, all available medical treatment is carried out. The result is additional painful treatment, often unnecessary operations to extend life by a few days or weeks. Quality of life or a dignified goodbye is rarely supported in this way. Medical staff, who see a dying person as being a personal failure, will try to keep terminal patients alive as long as possible. A hospital, which is more concerned in making a profit, will cause extra costs by administering additional treatment. Ambivalent comments from terminal patients caused by the feeling of a near death, are interpreted as having a psychosis, anxiety or depression, which has to be treated with a higher dosage of medication. This in return stops coherent conversation and causes loneliness.

2. The time factor for the relatives: Negative emotions should be avoided. Relatives talk about the patients, cry on the other side of the door and away from the patient. These white lies mean that more work is necessary in dealing with visitors and carers to agree on what to say and what not to say. They are playing a game of hope and they are wasting time. They believe they have more time than they really do, push important conversations into the future until it is to late. Unfortunately this avoidance means that there is no time left for loving and forgiving talks. The emotional hurdle grows higher. Honest talks and openness become more difficult and the pressure increases. This uncomfortable situation can make it unbearable. This means visitors stop coming or talking, at least about the subject they are thinking about and suffering from.

The focus is repression of the obvious. The reality is ignored, relative concentrate more on looking for mistakes in the past, what should have been done differently, diagnosed or treated differently. Guilty questions are put in the foreground and poison the atmosphere. The result is silence and asking for more treatment, pressure on the staff, more medication and activities. This again leads to more demand for a higher dosage of morphine, which impedes conversation. The relatives must come to terms with the idea that they didn't involve the dead person in the farewell and grieving process. After the death the relatives have to focus on their emotions, questions. Instead of rejecting emotions, the last hours should be used for honest and emotional talks, for forgiving and saying: "I love you" and accepting that life is finishing.

3. The last precious moments of a dying person: The terminally ill person fights against illness and wants to stay alive by all means. He sees the time of treatment as being a kind of 'time-out' which means that he puts happiness and quality of life into the future which he hopes to experience. An atmosphere of 'hanging in there' is produced and supported by the relatives, treatment and the doctors. "You have to look to the future, think positively and believe in your success!" is well-meant advice the same as "You are very ill, first the chemotherapy, than radiation and than will see what happens!" All this well meant and dishonest

advice impedes an honest conversation. The patient remains under pressure between doubt and wanting to believe and really depends on the clarity and honesty from his family. At the beginning he will follow the positive vision from doctors and family. Later he will doubt more and more which will result in losing trust in himself and in his carers. Should these disappointments bring about old reproaches or unsolved life-events, then bitterness and withdrawal increase. The patient feels more lonely and left alone with his disappointments, fear. All his focus is on himself his own pain which is then treated with more medication and will increase sedation.

Promises of healing and false expectations are as negative as disturbing the last hope. It is not an easy job and can only be successful through honest emotional and trusting conversation.

From a psychological perspective there is a correlation between pain, illness and sadness because people think it should not happen as it does. The nature of life is not accepted. A new culture demands that dying people should accept that the dying process is a natural part of life. Being aware of this will open new possibilities to say goodbye. A last conversation about the appreciation of life, about success, pride and experiences will make an emotional farewell possible. Agreeing on the process of death, the funeral and the inheritance can be talked about. The dying person can manifest his sense in life, re-conciliate unsolved points and take the left over time as present to leave in an open and peaceful atmosphere.
Grieving can be jointly experienced as a sign of deep love. Carers can than concentrate on the wishes a dying person might have and support his rights, needs and wishes.

In order to decrease negative outcomes, a new socially culture is necessary. The awareness of own death will be supported. This should be achieved by knowing the truth, writing an advanced directive and the last will and testament. It should support doctors and carers and bring down barriers concerning open conversation and emotions. This makes grieving easier and can make pain more bearable but is still not enough. Even after an emotional and successful goodbye, sadness and bereavement can hit much harder than expected. Relatives can be thrown off course. Easily accessible tools to support the bereavement process are necessary.

Most education and advice focuses on empathic conversation and releasing the pain. Supporting emotions, crying and sharing the feelings is the most offered help. There is no question, crying helps, but it is a scant offer of help. Together with clichés and volunteers with spiritual views or helper's-syndrom sadness and the feeling of loss can be manifested and spread itself pathologically.

Counsellers usually focus on clichés and sometimes subtly dictate the right way to die and grieve. In a negative case it comes about that

the mourners who are prepared to follow are kept in a re-traumatic mood whereby the ones who are shocked by the pile of paper tissues, have no chance to get help at all.
For both groups time will tell.

Palliative care and bereavement assistance must be able to offer tools and methods to join the client and fulfil his or her needs. I is our aim to support a positive bereavement process in time and to offer helpful tools which paces the clients view of the world. The counsellor must be able to follow the clients perspective and offer methods to help the client reach his own goals.

In the framework of the EU project: "Dying and Death in Europe" we asked educational institutes, the church and hospitals, which concrete assistance and methods were offered to solve mourning blockades and to achieve well-being. The methods offered are bereavement coffee shops, time and place for emotions, working with metaphorical pictures e.g. Fairy-Stories and spiritual guidance. In addition, psychotherapeutic treatment or drugs are offered. A lot of institutes have reacted with interest and have confirmed that there is a need for effective and easy accessible tools, especially to deal with deep mourning and bereavement blockades.

The partnership project focussed on positive and successful solved bereavement processes and came to the first conclusion concerning bereavement care and the solving of bereavement blockades. We published two relaxation meditation with the title "Yes to life" (www.psymed-verlag.de) and developed the "Bereavement Panorama Model" as an easy to learn and to use tool.

The first seminar was planned in January 2010 for the 16.-18. April 2010 in Warsaw. Unfortunately there was a tragical aeroplane accident, whereby 96 members of the Polish parliament were killed. Our workshop took place in this special atmosphere. The effectiveness of the method was tested on this extraordinary background and the spontaneous comments from the participants where very positive.

Dealing with death and dying shows that bereavement is also a contract given to the people left behind that they must sort out their own environment. Normally the bereavement process starts a long time before death, it starts with the diagnosis and then consciously, that there is only a little time left over.
This is the moment not to wrap each other in cotton wool, but to find a way to an honest and appreciative contact. The acceptance that life is finishing, will give space to deal with reality, pain, love and sharing feelings. This helps the

relatives to restructure their bereavement panorama naturally. If this doesn't happen, bereavement and suffering will manifest itself.

In the case off the unexpected sudden death of the Polish government, the bereavement process started with a shock. The Russian-Polish-Relationship was focussed on and historical memories, individual political expectations, hopes and fears where brought to attention. The 96 people, who died, were on their way to Katyn in order to remember the murdered people from 1940. In many massacars Stalin demanded that more than 22.000 polish people, officers, police , inelligance and other elite groups should be murdered to make it easier to govern the country. This brought to light special memories, fears and anxiety.

In the model of the Bereavement Panorama we assume that most people perceive their relationship to others in an inner social imagination of other people. This inside representation of a person determines how we rely on our relationships and influences our feelings and behaviour. A person who has passed away doesn't

disappear in mind, the memory is still there and in heart. Only the body has gone. That is the reason for being sad.

The Bereavement Panorama enables us to see how our clients assign their place among others. This insight will help to appreciate the life experienced, with the person who has passed away and will help to reorganize the representation of social reality. In practice this means that we project representations of dead and alive people around us. Where we place them, within this mental space, determines the relational and emotional meaning of the relationship. The emotional influence of those images provides a successful mourning or pathological progress.

The benefit of a Bereavement Panorama is that you don't need to let it happen by chance over time. The structure of the mental relationship can be worked out and the mourners can balance it out by changing the imagined place or submodalities of the dead person. Several mental techniques are offered to help the grieving person to find his or her emotional balanced panorama.

Bereavement is an active process you don't choose to have, but at least you can put it together yourself. The Bereavement Panorama is both, helpful and easy to learn. Especially vo-

luntary workers dealing with death and bereavement can use this tool to support this natural mourning process.

A Bereavement Panorama-workshop will take place in Hamburg on the 25. - 26. Februar 2011. We will offer education and self experience with the Bereavement Panorama Model. Information can be found under www.ecp-akademie.de/partnership.

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