# Informal caregivers in critical end-of-life situations (Summary)

Beat Sottas, Sarah Brügger, Adrienne Jaquier, Delphine Brülhart, Laura Perler

## 1. Objectives of the research project

Starting from the observation that the last years in peoples' lives are increasingly being accompanied by progressive illness and the fact that an important part of the care needed at the end of life is provided by family members and other informal caregivers, the research project focused on informal caregiving in end of life situations at the patients' home. Although many people wish to die at home and despite a great willingness of informal caregivers to provide care, the number of people dying in institutions increases. Hospitalizations at the end of life are not only highly disruptive, very often they are also futile. It is thus assumed that many hospitalizations at the end of life could be avoided if informal caregivers had received adequate support. Accordingly, the project focused on critical situations where a person would have liked to die at home but where different problems and challenges led to unnecessary hospital admissions and/or an unsatisfactory caregiving experience for the people concerned.

**The main objectives of the project were to identify the criticality of end of life situations as perceived by informal caregivers and to explore the support and advice needed by informal caregivers to manage these critical situations.**

In detail, the different objectives according to the proposal were:

- to identify critical situations in the provision of end of life care at the patient's home as seen by informal caregivers, and to explore differences in the assessment and definition of critical situations by different persons in different contexts;
- to explore and understand different ways of decision making and coping in critical situations, and to identify relevant institutions and services where support and advice is sought when being confronted with a critical situations;
- to identify – from a laymen perspective – gaps in service provision, missing competencies of and inappropriate assessment by formal care providers, and inexistent or unsuitable equipment leading to inappropriate hospital admissions;
- to compare the identification and handling of critical situations by informal caregivers in the German speaking parts of the cantons of Fribourg and Valais and in the French speaking parts of the same cantons, exploring the differences in attitudes, motives, expectations, values, behaviours, and competencies of informal and formal caregivers and how they affect the decisions at home and with respect to the institutional interfaces and standards;
- to explore what kind of technical, instructional, psychological and spiritual support is needed in order to enable informal caregivers to cope with critical end of life situations which lead to avoidable hospital admissions;
- to develop, test and provide instructional material and tools to enable and empower informal caregivers in the context of home-based end of life care;
- to disseminate examples of good practice leading to the improvement of home-based end of life care and to a better quality of life for patients and caregivers as well as for policy makers and the public.

## 2. Research design, theoretical framework, methods and data

Research was conducted in the two different linguistic regions in the cantons of Fribourg and Valais. As the project was seeking to understand the topic from the perspective of the informal caregivers, the main part consisted of narrative interviews with current and bereaved informal caregivers. Because current and bereaved caregivers may differ in the way they are judging their experiences, both categories were included in the study. The interviews were guided by key questions focusing on situations considered as critical, contacts to the formal health care system, their role, activities, decisions and problems concerning the care they are or have been providing.

25 informal caregivers have been interviewed. Interviews lasted from one to three hours and took place face-to-face at the home of the informal caregiver or at another place chosen by them.

With bereaved informal caregivers, only one interview was conducted. The current informal caregivers were recontacted by telephone up to three times after the initial interview to learn about changes in the patient's and/or caregivers situations and about critical situations which may have happened in the meantime.

In addition to the interviews with informal caregivers, interviews and focus groups with health professionals active in home-based care, with administrators, with coordinators of volunteer-organizations, with general practitioners and specialists, and with representatives of different associations active in the field as well as two focus groups with informal caregivers were conducted. They were asked to comment our preliminary results obtained from the interviews with informal caregivers and to challenge our interpretations. This kind of dialectic interaction assisted in raising new questions, gaining further information, testing preliminary categories, and looking for commonality and differences among the participants' stories.

For data analysis, a grounded theory approach using constant comparative method (Glaser/Strauss 1967, Harry et al. 2005) was used. All interviews were audiotaped and transcribed verbatim. The researchers read the transcripts independently, identifying recurring, converging and opposing themes and patterns, key concepts, illustrative examples from the data and possible linkages to concepts derived from the literature in order to generate a list of preliminary codes. The codes were then compared and discussed in the team in order to develop a common coding scheme which was continuously adapted as further interviews were analysed.

Although applying a grounded theory methodology which starts with data collection rather than a hypothesis or a theoretical framework, the research was guided by different theoretical perspectives and by existing research findings. The most important models and theoretical frameworks which we have taken into consideration are the transactional model of stress and coping by Lazarus and Folkman (1984), the caregiving and stress process model by Pearlin et al. (1990), the ecological systems theory of child development by Bronfenbrenner (1979), the model by Gomes and Higginson (2006) identifying factors determining the place of death, and the concept of resilience (Anaut 2005).

## 3. Results

The following chapters summarize the results of the project:

### Reasons for inappropriate hospital admissions

Based on a literature review and the interviews with informal caregivers and professionals, the following reasons for inappropirate hospital admissions could be identified:

- In the last days of life, many people suffer from symptoms like weakness and fatigue, reduced appetite, pain, dyspnea, constipation, depression, anxiety, and sleeping disturbances. If informal caregivers are not well prepared and equipped to adequately interpret, understand and manage these symptoms, their appearance may lead to psychological stress and the caregivers may make an emergency medical call or drive to the next hospital. In-hospital treatment is often the result and may end with an “acharnement thérapeutique”[1] by using advanced interventions. Afterwards, the caregivers may feel guilty because they have not been able to fulfil the wish of an end of life at home.
- Missing knowledge in palliative care by family doctors and other health professionals, inappropriate decisions or insufficient support are further reasons for the hospitalization of patients who could very well have remained at home. We found cases where health professionals misinterpreted symptoms, made wrong decisions and initiated erroneous procedures. Another factor leading to hospitalizations is sometimes their refusal to make home visits.
- Hospitalizations often take place at night when the only available medical contact in case of a problem is the emergency departement at the hospital. These hospitalizations could often easily been avoided if the caregiver had the opportunity to call someone with a knowledge in palliative care and to ask for advise.
- Sometimes, hospitalizations take place independently of the patient’s health condition. It is rather the caregiver’s manifold exposure to emotional, social, spiritual, psychological and practical challenges which makes them feel tired and overburdened, making it impossible for them to continue to provide care at home.
- Financial reasons can also lead to a hospitalization as the costs for the family are in general significantly higher when the patient is cared for at home. Additionally, caregivers may be obliged to reduce their working hours, resulting in a lower income and a penalty on their pension scheme.

Factors which can help to avoid hospitalization at the end of life are close and trusting relationships within the family as well as the involvement of different people who are sharing the responsibility of care and who support each other.

### Burdens and challenges in general

We soon discovered that the focus on inappropriate hospital admissions is not sufficient in order to understand the experiences of informal caregivers. First, we found that not every hospital admission which is inappropriate from a medical point of view is experienced as unwanted or unsatisfactory by the informal caregivers. In some cases, dying at home can overburden family members. They may anticipate inadequate caring capacity and therefore decide to admit the dying person to a hospital. In several cases, this was considered by our interview partners as the best option as it took away anxiety and improved the relationsships within the family. Second, we also discovered care arrangements where no hospitalization took place, but where caregivers faced a great burden and still suffer from physical and psychological health problems even a long time

---

[1] Health Canada uses the terms “therapeutic eagerness” or “therapeutic obstinacy”

after the patient's death. Therefore, in order to capture the experiences of informal caregivers in a comprehensive manner, we extended the focus on burdens and challenges in general. The term "critical situation" is now used to mean every burden or challenge experienced as "critical" from the point of view of the informal caregivers, regardless of resulting in a hospitalization or not.

The obstacles and challenges which are repeatedly mentioned in the interviews (and which partly correspond to the reasons for inappropriate hospitalizations) are: lack of knowledge about available support services, high cost of home-based care, (too) many actors involved, professionals lacking time and capacity, insufficient and/or inappropriate support from the health and social care systems, lack of knowledge about caretaking and nursing, missing equipment, high demands and often unconcerted procedures regarding administrative issues, feeling left alone, (too) high and ambivalent expectations, missing knowledge about the process of dying, spiritual questions, and poor communication by professionals. It can be observed that in many cases the informal caregivers are too busy and too tired to notice their exhaustion and to search for help.

## Five different categories of straining emotions

After finalizing data collection and analysis, it can be concluded that the various stressors encountered by informal caregivers lead them to experience five different categories of straining emotions. It became apparent that it is less the stressors themselves, but more the type of emotions experienced by the caregiver which influence how the caregiving situation is perceived by the caregiver. The following chart shows the straining emotion, the stressors which lead to this emotion and a citation from our data to illustrate the emotion described:

| **Straining emotion** | **Stressors** | **Quote from interviews** (translated from German or French) |
|---|---|---|
| Feeling tired and overburdened | Due to the strain of caring, the lack of sleep and the variety of tasks | "Before he died, my husband was at home for three weeks. I took care of him 24 hours a day. It was tough. I don't think I could have done it any longer." |
| Feeling alone and abandoned | Due to a lack of support and the difficulty of finding someone to talk to | "It is possible to be surrounded by friends and family - and still to feel completely alone. I had the feeling that no one was really able to understand the situation I was in." |
| Experiencing grief and fear | Due to the confrontation with illness and death | "The most difficult part was knowing that we would be separated. I had no idea what the future without my husband would bring. And I had no idea where to find the necessary strength to go on." |
| Feeling helpless | Because of the lack of knowledge about the illness, possible symptoms and best-practices in caring for a person at the end of life at home | "You see this person suffering and there is absolutely nothing you can do. You are next to him and you are absolutely helpless." |

| | | |
|---|---|---|
| Feeling having lost control over one's own life | Because of societal expectations, pressure from the family and a paternalistic health care system | "I was shouting out loud because I didn't want to be the one giving morphine to my father. But no one listened to me. At the end, it was still me who had to do it. It was horrible." |

It is highly subjective whether or not a stressor is leading to a straining emotion. It depends on the personality and competences of the informal caregiver, and the available ressources.

## Strategies by informal caregivers to cope with critical situations

To cope with the straining emotions mentioned above, the informal caregivers actively seek help and support, inform themselves and acquire skills and competencies, talk to others, allow themselves time off and emphasise the positive and meaningful aspects of caring for someone at home.

One of the main results is that the main ressources used to cope with the different burdens experienced by informal caregivers are personal competencies and personality traits as well as the help and support by the informal network. Although formal support services are involved as well, they play only a minor role in comparison and they are therefore hardly sufficient for a successful caregiving experience. As a fair and comprehensive health care policy should allow informal caregivers to provide care at home - even when support by the informal network is not available - changes in the currently established support systems are necessary.

## Relevant institutions and services where support and advice is sought

One of the first steps when analyzing the interviews was the identification of all the actors who currently play a role in home based palliative care. Starting from the narratives of the informal caregivers, a network of all the actors implied was drafted, stating not only the relationsships, but also their quality.

An important part in supporting informal caregivers is in general played by home care services (Spitex) or independent nurses. They don't only help with the care for the person at the end of life and – in some cases - household tasks, but they assure also an important link between the home and the formal care system. Besides, family doctors – at least if they are willing to make home visits – are another important resource for informal caregivers. On the other side, informal caregivers often experience a lack of support when the patient is treated at the hospital. There, they often complain about not receiving enough information and explanations, and not having the possibility to talk to the health professionals caring for their family member. Another complaint repeatedly addressed in the interviews concerns the fact that in the hospitals everything is made to prolong the life of the patient, and the possiblity of him or her dying is hardly taken into consideration. Many informal caregivers, however, would prefer an open communication regarding the approaching death, an earlier inclusion of palliative care, and more support in accepting death and dealing with sorrow and grief. In cases where the caregivers were informed about the approaching death, they sometimes complain because this had been done in an insensitive way.

Besides nurses and doctors, other services like health care leagues or volunteer assocations also play a role in supporting informal caregivers. However, our results show that only few caregivers make use of their services. Very often, they do not know about these opportunities and offers, and in many cases they are too busy and overwhelmed with their daily tasks and they do not have the time to search for help and support. Accordingly, it was repeatedly said that more information about the available services would be needed.

As already written above, the care networks reveal that one of the most important sources of help and support is found among family members and friends. Also, personal competencies by the caregivers themselves play an important role.

All in all, when studying the different care-networks, the number of different formal and informal actors who play a role is striking. We discovered cases with up to 30 different actors involved. What is however missing in most cases is an instance which helps the caregiver to coordinate all the various actors and to fill the gaps which nevertheless still exist.

### (Further) gaps and problems in service provision

Starting from the observations made in the preceding chapter, we continued to explore the **relationship of the informal caregiver to the formal health care system** and the role the informal caregiver is allowed to play within healthcare by the professionals.

First of all, it must be emphasized once again that it is the informal caregiver who plays the main role in providing care for a person at the end of life at home. In a system where up to 30 different actors are involved he/she is the one who is responsible for coordination and management. Besides, although formal and informal help is included, it is the informal caregiver who is present most of the time and who assumes most tasks. He/she is the one who knows the patient best and who can therefore provide important information needed for an optimal care. Nevertheless, it can be observed that from the perspective of the health professionals the informal caregiver is still most often seen as a "co-patient" and not as a partner or expert. In order to provide the best possible care for the person at the end of life and also to respond to the needs of the caregivers, it is necessary that they are accepted as equal partners in the provision of care and that their expertise – which is different but complementary to that of the health professionals – is taken seriously.

Another aspect to be mentionned in this context is the **missing interprofessionalism and the territorialism** of the different health professions which could be discovered and which make the experience of the informal caregivers even more difficult.

A further problem we have identified concerns the **definition and application of palliative care** as it is currently used and practiced. As it has already been mentionned, many caregivers would prefer if death was less a taboo in the curative oriented hospital world, and if palliative care would be considered earlier in the course of the illness. As we have discovered, only very few patients at the end of life receive palliative care. Much more common is the complaint by family members of being used as a guinea pig and of burdensome treatments even a short time before the patient's death. We have therefore questioned the current use of the term "palliative care" and its application in the health care system and came to the conclusion that – in view of the changing epidemiology – a broadening of the meaning of palliative care is necessary.

### Comparison of the identification and handling of critical situations in different contexts

Differences in assessment and coping strategies according to region could not be assessed as too many different factors influence the experiences of informal caregivers. The heterogeneity of the different cases and the qualitative study design we had chosen made it impossible to identify interregional differences – with one expection. The one obvious difference between Valais and Fribourg is the fact that in Valais palliative care structures are already established for some years while in Fribourg, a mobile palliative care team started only in 2009 as a pilot project in one part of the canton. Most of the caregivers from Fribourg who participated in our project were therefore not supported by a palliative care team. For the informal caregivers, the possibility to be accompanied by a mobile palliative care team as it exists in Valais and especially the possibility to contact someone anytime – that is, also at night – with open questions of any kind is a crucial factor, making them feel much more safe and secure, preventing them from feeling left alone and being afraid of making wrong decisions. Therefore, the availability of a 24-hour emergency number is one of the most important aspects when planning support measures for informal caregivers. Even when no phone call is made at night, informal caregivers feel much more safe when they have the possibility to do so.

**Gender-specific concepts, ascriptions and norms**

Although, the interregional comparison didn't lead to the expected results, analysis revealed another factor explaining many differences in assesssment and coping strategies by informal caregivers. Our results show that informal care for people at the end of life is in many ways shaped by gender-specific concepts, ascriptions and norms.

First of all, it is known that women are more often informal caregivers than men, although men catch up. As a result of the still dominant traditional division of labor informal caregivers are mostly female. However, in Switzerland in the last few years the number of male informal caregivers is increasing. According to different studies, male informal caregivers mostly take care of their wives or partners, are usually older than female informal caregivers, invest less time in informal caregiving, and feel less burdened from caregiving than women.

The results of our study reveal several gender differences which offer explanations why female informal caregivers experience more burden than male informal caregivers.

- in the narratives of male informal caregivers the taking over of nursing tasks is an important subject. To take over those tasks which are typically seen feminine is legitimized by the men with the love and affection to their wife/partner.
- female imformal caregivers emphasize the "naturalness" of their activities. This leads them to experience much more internal and external pressure than men do.
- men who engage in providing care for relatives get more recognition and support than female caregivers – not least from health professionals.

## 4. Recommendations for policy makers and experts from the practical realm

One of the objectives of our research project was the exploration of the needed technical, instructional, psychological and spiritual support in order to enable informal caregivers to cope with critical situations. Based on our research results presented above, our recommendations for improving support and services for informal caregivers are as follows:

Care provision

Informal caregivers need more and appropriate support from the health and social care systems. Although the interview partners were in general satisfied with the medical and nursing care the patient was/is receiving, there are several aspects that could be improved.

- ➔ Due to structural, institutional and/or financial constraints, existing medical and nursing services are often not able to reply in a flexible and timely manner which is adapted to the needs of caregivers and patients. Especially in end of life situations which are often unpredictable and quickly changing, **flexible and rapidly available services are needed**.
- ➔ Absolutely necessary is the availability of **out-of-hours and night support** for informal caregivers, p.ex. through a telephone helpline. At night, when normal healthcare services are not available, caregivers are particularly vulnerable and any critical situation may lead to an unnecessary hospitalization if not other contact is available.
- ➔ Besides help with personal, nursing and medical care, that is, help in managing the patient's symptoms, caregivers need much more – and this is where significant gaps exist. Care provision must also **include spiritual, emotional and psychological support** - and

this throughout the illness trajectory. Many informal caregivers express the wish to have "someone to talk to". They need to be helped to prepare for the loss of the patient before death and also be offered bereavement support afterwards.

- ➔ It was discovered that only very few patients had access to palliative care services. In view of improving the quality of life for the patients and their families, a **broadening of the target group of palliative care and an integration of its philosophy in general healthcare** is necessary. Palliative care may play an important role already at the time of diagnosis.
- ➔ Regarding support and services for the caregivers (in opposition to services for the patient), it is important to **actively approach informal caregivers** because they are often too busy – or focusing solely on the patient - to notice their own needs.
- ➔ A comprehensive support systems for informal caregivers includes **help with administrative issues**. Dealing with all kinds of insurances and covering instruments, different service providers, organizing equipment, etc. is an important and time-consuming task when caring for someone at home.
- ➔ One of the main challenges informal caregivers are confronted with is the high number of different actors and institutions they have to deal with. Doctors and nurses are often not aware that not only medical and nursing personnel is involved, but also many other formal and informal actors. It is thus essential that policy makers and health professionals **pay more attention to the aspect of coordination**. Many informal caregivers express the desire to have **one key person or institution** they can contact for any problem and who helps them with organizing and coordinating the different services and actors.
- ➔ Currently, there is a strong focus on enabling people to die at home. However, if informal caregivers are to fulfil the role the political agenda is assigning them, they also need breaks and rest times (as do professional caregivers). Care provision must therefore include affordable possibilities for **respite**.

Information and preparation for informal caregivers

One of the main gaps which our research project has revealed concerns the missing information and preparation informal caregivers are currently receiving.

- ➔ In order to avoid unnecessary hospitaliziation and to help informal caregivers in dealing with difficulties they need to be **prepared for caretaking and nursing**. This means, they should receive education on the nature of the disease and disease progression, practical nursing information (p.ex. how to lift the patient), information on medication, nutrition and symptom control, etc. It is especially important that caregivers are better prepared and equiped to interpret and manage the symptoms from which many people at the end of life suffer. More knowledge about the process of dying could help to reduce fear and anxiety. Additionally, clinical information would help the caregivers to actively take part in the decision-making process throughout the process of the disease.
- ➔ Besides, informal caregivers need to be better **informed about available support services and practical aspects** of caregiving (where to get equipment, which benefits they are entitled to and how to claim them, etc).
- ➔ Education on how to offer emotional support to the patient and how to deal with grief, loss and bereavement within the family may also be necessary. Educational programms should include **emotional, social, spiritual and psychological aspects**. Caregivers need information on how to minimise the burden placed on them and how to survive the

experience. As already mentionned above, this kind of education should be offered automatically as caregivers tend to ignore their own needs.

➔ Educational programms that take place out of the home may sometimes be problematic for the caregiver, due to lack of time. It is therefore more appropriate to offer **education and information at their home** and adapted to their individual situation and needs.

### Financing

➔ The high costs of home-based care in comparison to care in an institution (for the families) has been a recurring subject in the interviews. A rethinking of financing schemes and more **financial support for informal caregivers** is therefore a critical factor in enabling people to remain at home.

➔ A **simplification of administrative issues** in claiming financial support would reduce significantly the burden of informal caregivers. Current practice results in many people not claiming benefits they are entitled to because they do not know about them and/or do not know how to proceed.

### Education and training for health professionals

➔ Missing communication between different health professionals and mind sets fixed at professional territories are common. In order to provide comprehensive and continuous care for patients and their families, health professionals need to be better **prepared to work in interprofessional teams** and to communicate and coordinate with professionals of different backgrounds.

➔ Too often, informal caregivers are exclusively seen as co-patients by health professionals. Educational programms should contribute to a better understanding of the central role informal caregivers are playing in the process of care and **encourage their involvement as partners and experts**.

➔ Family doctors and other health professionals at the front line need better **knowledge in palliative care** in order to avoid a hospitalization or “l’acharnement thérapeutique” with too aggressive treatment in the last days of a person’s life.

➔ A common complaint by informal caregivers is poor/insensitive communication by health professionals. Therefore, education and training – especially for doctors – should focus much more on teaching **how to communicate with patients and families** who are confronted with an incurable illness.

➔ Health professionals also need **to be aware of gender ascriptions and other norms and expectations** which might influence their way of dealing with different informal caregivers.