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Abstract

The aim of this study was to develop a classic grounded theory of palliative cancer patients and their relatives in the context of home care. We analyzed interviews and data related to the behaviour of both patients and relatives. "Living on hold" emerged as the pattern of behaviour through which the patients and relatives deal with their main concern, being put on hold. Living on Hold involves three modes: Fighting, Adjusting and Surrendering. Mode being may change during a trajectory depending on many different factors. There are also different triggers that can start a reconciling process leading to a change of mode. This means that patients and relatives can either be in the same mode or in different modes simultaneously. More or less synchronous modes may lead to problems and conflicts within the family, or with the health professionals.

Keywords: adjusting mode, fighting mode, grounded theory, palliative care, surrendering mode

Introduction

Receiving a cancer diagnosis requires emotional and physical adaptation to a new situation (Flanagan & Holmes, 2000) and when the cancer is incurable, both patients and relatives may confront a life crisis (Kristjanson & White, 2002). Powerlessness and helplessness are common feelings among dying patients (Sand, Strang, & Milberg, 2008), but at the same time they can experience hope and quality of life (Melin-Johansson, Odling, Axelsson, & Danielson, 2008). Patients want to be treated as persons not as diseases (Wenrich, Curtis, Ambrozy, Carline, Shannon, & Ramsey, 2003) and cancer patients want palliative care to be based on safety, participation and trust (Harstade & Andershed, 2004). Adequate information and support in the early phases of treatment is thus important and can better fulfil future needs, render increased trust, and provide confidence throughout the course of the disease (Kristjanson & White, 2002).

The patient's cancer disease also changes the situation of their relatives (Stajduhar, 2003), who may be emotionally overwhelmed by unprocessed emotions (Thomas, Morris, & Harman, 2002). If dying patients are to be cared for at home the well-being of their relatives is crucial (Ramirez, Addington-Hall, & Richards, 1998), and their commitment is often seen as a condition for good home care (Mok, Chan, Chan, & Yeung, 2003). Yet, relatives living nearby are not a necessity for providing quality palliative care (Gyllenhammar, et al., 2003).

When patients and relatives are in different phases of their processing of overwhelming emotions, it can be difficult for health professionals to understand their emotional reactions (Fox, 1995). There can also be a mismatch of perceptions as to what is important between patients, relatives and professionals (O'Baugh, Wilkes, Luke, & George, 2003; Widmark-Petersson, von Essen, & Sjoden, 2000). In order to offer support at the right care level, health professionals need a better knowledge of the patients' and relatives' situation in palliative cancer care (McIllmurray, et al., 2001).

In the last decades there has been a shift in the place of dying and more people die in their own homes (Burge, Lawson, & Johnston, 2003; Socialstyrelsen, 2006), which increases the demand for home care (Fürst, 2000). Studies on patients' and relatives' situation in palliative care have mostly been conducted in hospice and advanced palliative care settings, but there is a lack of studies from acute care and basic home care settings, and a considerable lack of explanatory theories of how patients and relatives handle their situation in home care. The aim in the present study was therefore to develop a grounded theory of palliative cancer patients and their relatives in the context of home care. The research question guiding the study was: What is the main concern for palliative cancer patients and their relatives and how do they resolve it?

Method

Classic grounded theory was chosen since it suited our research question. The grounded theory methodology aims to discover the participants' main concern and to conceptualize patterns of human behaviour (Glaser, 1978, 1998). In this study, our theory aims at explaining the patterns of behaviour of palliative cancer patients and their relatives in home care.

This study was carried out between 2006 and 2008 in six different rural communities (total population 180,000) in the south of Sweden. At the time of the study, the area had no advanced palliative care services on a 24-hour basis. Instead, a palliative counselling team, consisting of six nurses and two physicians, served the population daytime Monday to Friday. The palliative counselling team was affiliated with the hospitals, working as a link between the hospitals and the community based nursing home care in providing support to healthcare professionals.

This study was approved by The Regional Ethics Committee of Lund University, Sweden (LU 680-3) and by those responsible for home care in the municipalities involved. Written informed consent was obtained from participants before the interviews. In all, data from 25 formal interviews were coded and analyzed. Consistent with the grounded theory concept "all is data" (Glaser, 1998, p.8) we also analyzed field notes and memos from informal interviews and participant observation at cancer care conferences. The included patients had various cancer diagnoses at different stages and with different prognoses. All data was related to the behaviour of both patients and relatives in palliative care and was constantly compared with the formal interview data. Data collection was guided as much as possible by theoretical sampling (Glaser, 1978), data collection and analysis were done simultaneously and field notes were written during interviews (Glaser, 1998, 2001). When interview data ceased to contribute to the emerging theory a theoretical saturation was reached and data collection ended (Glaser, 1978).

The interviews were all conducted in the homes of patients and relatives, either interviewing them together or separately. The main researcher (AS) began the interviews with open questions to allow the patients' and relatives' answers unfold without any direction from preconceived questions. Consequently, the interviews resembled open conversations more than formal interviews. The patients and relatives were asked to tell the researcher about their trajectory and current situation. While interviewing and also while analyzing, new ideas emerged of what to ask next and later on. More specific questions were asked to saturate the categories and concepts in the theory. Due to the delimiting properties of grounded theory, the interviews could have been shorter by the end of the study, but since patients and relatives had so much to share it was difficult to end the interviews. The interviews therefore lasted between 60 and 180 minutes.

Directly after each interview more field notes and memos were written and analyzed. During open coding, incidents articulated in the data were analyzed and coded. The open codes were then compared with each other followed by comparing newly generated concepts to new open codes. The concepts were then compared to other concepts. When the core concept had emerged, selective coding began to delimit the coding to concepts related only to the core concept, which was a template for further data collection and theoretical sampling (Glaser, 1978). In this phase, secondary analysis was also done on data that had been collected in earlier studies choosing the most comprehensive interviews. The purpose of the secondary analysis was to refine the concepts and delimit the coding only to variables related to the emergent core concept.

During the entire study we wrote conceptual memos to capture creative ideas. A rich memo bank was developed through the memo writing and we also wrote memos on already written memos. In the theoretical coding, we looked for relationships between concepts and the core concept by hand sorting the memos. As a last stage, the sorted memos were written up to the theory, Living on Hold. A literature review was not done until the substantive theory was formulated and it was then used as another source of data in the constant comparative process (Glaser, 1998).

Living on Hold

To be put on hold emerged as the main concern for patients in palliative cancer care and their relatives. They are constantly waiting, their lives being put on hold. They are also losing control of their normal existence which is cracking and falling apart since life conditions are radically deteriorating. At first this affects patients more than relatives. But during the disease trajectory the relatives' normality is also broken. Patients and relatives are living in a waiting mode, entering a world of uncertainty. In the waiting mode, they can be overwhelmed by feelings of powerlessness and loneliness, decreased freedom, and fear of being dependent. They are also caught in a weak body, a bitterness trap and the overtime trap. Overtime trap means that the patient lives longer than expected, resulting in friends "giving up" and stop visiting. They can also be trapped by the disease and trapped in their home.

While being put on hold, patients and relatives are trying to handle the fact that their normality is breaking down through different mode behaviours. There are three mode types by which patients and relatives are Living on Hold: the Fighting mode, where they are striving to renormalize their lives; the Adjusting mode, where they are adjusting to a life on hold and creating a new normality; and, the Surrendering mode, where they are releasing control of normality and surrendering to a life on hold (Table I). Mode behaviour type depends on age, personality, the cancer diagnosis and prognosis, social network, earlier experience of crisis, the health professionals' competence, and continuity of care. It should be emphasized that one mode is not better than another. Modes are experienced individually and different persons can be more or less involved in the strategies of any particular mode. Mode being may shift during a disease trajectory by triggers that start a reconciling process leading to possible mode change.

Table 1: The theory Living on Hold

Reconciling process Mode shifting triggers	**Fighting mode** Renormalizing Rebelling Blaming Foreseeing Scrutinizing Fighting evaluating **Adjusting mode** Moment-living Disease diminishing Façading Adjusted evaluating **Surrendering mode** Total trusting Releasing control Surrendered evaluating

Reconciling

A reconciling process is the connecting link between the three modes of fighting, adjusting and surrendering. Reconciling means that patients and relatives are evaluating their current situation, the life they have lived, how it turned out, and what they could have done differently. By reconciling, patients and relatives are evaluating their current situation and near future, where after they may stay in the same mode or shift modes. Patients and relatives can either be in the same mode or in different modes simultaneously. Less synchronous modes can lead to problems and conflicts within the family, or with health professionals.

Evaluating is done regularly in all modes, but the evaluating content varies in the different modes as will be further explained below. But even if patients and relatives are evaluating life, this alone does not lead to a mode change. Yet, it is a necessary foundation for the reconciling process. So without evaluating, there is no reconciling process.

Different mode shifting triggers may appear at critical junctures when evaluating life. The triggers do not have to be strong since there is a hyper perceptiveness and a magnification of details due end of life vulnerability. High sensitivity to small situational changes may cause suboptimal care and communication failures. When patients or relatives identify suboptimal details in the care, it may lead to increased or decreased willingness to fight and stay in control. Experiencing a new symptom may trigger more fighting. Other triggers can be receiving bad news, dependency experience, or feeling ignored, lonely and uncertain.

By reconciling, the patients and relatives are evaluating their situation and actual mode being. They are unconsciously assessing whether triggers are worth noticing or could pass without any mode change. The sensibility for triggers depends on factors such as individual personality, earlier experiences and the degree of support received. Reconciling does not always end in a mode shift. Even if the same triggers start a reconciling process, it can lead to a mode change for one person while another remains in the same mode as before. Several fast modes may shift during a short period of time and, depending on the patients' and relatives' mood, could be energy draining for all involved.

Fighting mode

In the fighting mode, patients and relatives are striving to renormalize their lives. Sustaining normalcy is desired; they only want to return to the normal lives they had before the cancer literally took over. The fighting mode strategies other than renormalizing are rebelling, blaming, foreseeing, scrutinizing, and evaluating, and patients and relatives could be more or less involved in these strategies.

Renormalizing

Renormalizing means regaining normalcy and hanging on to the image of normality. This involves strategies such as managing self and keeping track. They want to decide and handle things by themselves, since being dependent on others leads to decreased freedom. They can accept help, but eventually it is up to them to decide what to do. Keeping track of everything that happens enables them to handle the world of uncertainty. Although it can be energy draining to regain normality, they are discovering potential powers that they were unaware of. This reserve capacity emerges unexpectedly when needed offering unknown innate powers to overcome obstacles which otherwise would be insurmountable. These newly discovered hidden strengths renew the energy to keep on fighting.

Rebelling

Rebelling means protesting and fighting against the disease, not accepting the situation, and least of all, not accepting a life on hold, because they have more to give and to live for, and they are not ready to die yet. It is especially difficult when a patient does not feel sick, but they know they are dying soon. The rebelling is often done against the health care system in order to find someone or something to blame for what happened; and this can cause conflicts with health professionals. Rebelling may lead to increased involvement in the blaming strategy.

Blaming

Through blaming, patients and relatives find someone or something to accuse and to be the guilty one. They may seek reasons for becoming ill; they may blame themselves for the cancer (e.g. smokers). When it comes to the disease, they blame themselves for not seeing the doctor in time, rationalizing that it was too late for cure when they finally entered the care system.

They ruminate over whether they could have done anything differently in life to prevent their situation; e.g., they should have had more time, life is unfair and they feel cheated.

Sometimes patients and relatives vent blame and flash out anger. The emotional displays can be misunderstood by health professionals or even by their family. An open atmosphere is important where these feelings of blame can be expressed. Accusing and blaming can eventually trap them in bitterness making it difficult to evaluate and reconcile their life.

Foreseeing

Foreseeing is needed to keep full control over life even though it is put on hold. Through foreseeing, they can stay in control and be a part of their care. They are continuously seeking anticipatory care, which means trying to foresee what will happen concerning the disease and potential symptoms; staying ready for every possible situation that might occur. They are also seeking confirmation to reduce the uncertainty caused by their life being put on hold. If they receive sympathy or pity instead of confirmation, they can lose their trust in others. The resultant lack of self-confidence can lead to mode shifting.

Even though patients are fighting and planning ahead, they are anticipatorily mourning their life and the normality that soon is gone. They have to be strong and keep fighting, because if they feel ready to leave this earth and face death, this means that they have given up. Foreseeing means planning for the moment but also planning for a time after death. Although they do not really want to face it, they need to feel assured that everything will go well, even when they have to leave this life.

Scrutinizing

Scrutinizing everything around them is a consequence of their hyper sensitivity and their involvement in rebelling, which makes them suspicious and distrustful. They are sensitive to the health professionals' uncertainty and ignorance. Since they need to control everything, they scrutinize the professionals to see if everything is done right. They are also scrutinizing their own lives through revaluating. Life is often experienced as an emotional roller coaster, where they seek to have complete control, which takes energy and affects their emotions.

Fighting evaluating

By evaluating, patients and relatives are thinking of their lives as lived and the choices they have made or should have made. When evaluating life, they can discover things or opportunities that could have been different and this may cause bitterness. Blaming is an important part of fighting evaluating. Yet, they are not ready to give up; they believe they have a lot of things to live for. They value a life still worthy of fighting for.

Adjusting mode

In the adjusting mode, patients and relatives learn to live on hold by adjusting to a new normality and new routines. They try to adjust to the new situation, but they do not let the disease control their lives. They change their lives so that the disease does not affect it, doing their best according to the situation. They adjust to a life put on hold by moment-living, diminishing, façading, and evaluating.

Moment-living

Moment-living involves a total presence in the here and now; a present living. Moment-living is done through maximizing life; making the best out of every situation. Maintaining everyday routines is important; not letting the new life on hold affect them. They adjust their lives so as not feel powerless or crushed by the disease. They do not like it, but have no choices. *This is life and you can't affect it, it just happens.* Moment-living is done by optimizing living, which means taking every chance to be happy and enjoy life with the attitude - *it is now that counts.*

Moment-living leads to planning for daily life, both practically and physically; not making any plans for the future, just living here and now. Although they want some control over their lives, patients and relatives do not need full control over everything that happens or will happen. *You can't foresee everything and so why worry in advance?* With this attitude, it is difficult for professionals to engage in anticipatory caring.

Disease diminishing

Patients and relatives use disease diminishing to work past the disease and turn it into something that exists but that doesn't dominate their lives. *Life must go on.* Diminishing is done by re-routining to create new routines, adjusting to the situation, and making the impossible possible.

Diminishing also means facing the disease but not accepting it. It is relegated to the side yet they are well aware of it. *That's life, so why not me? Now it is like this and I have to do the best of it.* Disease diminishing also entails not involving more people than necessary from outside the family in order to try and manage by themselves as long as possible.

Façading

Façading is a powerful way of adjusting to a life put on hold. Façading means keeping an emotional façade and staying emotionally strong, no matter what. Patients and relatives do not show any feelings or do not share any thoughts to anyone outside the family. Façading is facilitated by strong disease diminishing. Façading could also be done within the family as a protection or as a shield from the fear of being abandoned. From an outsiders' point of view, this could be perceived as a cold attitude and unawareness of the disease and palliative care goals; acting like nothing is wrong and that they are going to live forever, though health professionals know they are well aware of diagnosis and prognosis. Patients and relatives are aware that death is approaching, and they know they have to go through it, but it should not affect their lives more than necessary. So there exists a closed awareness within the family; they keep the disease almost as a secret through disease diminishing. Since they do not want the disease to affect family life, they avoid talking about it and anything that reminds them of the disease. This leads to difficulties when professionals want to talk about palliative care because if the family talks about it, it reminds them of the approaching death. One possible consequence is that well-meaning professionals talk too much of the disease and what might happen.

Adjusted evaluating

Patients and relatives evaluate what is important in life and what really means something in this world. Evaluating can lead to changed values and attitudes; to seeking a second chance in life by moment-living and making the most out of it. Another important strategy is thinking optimistically. *If I wouldn't be sick, someone else would be sick, and therefore it is better that I am sick.* They do not blame anyone, since there is no one to blame and they do not feel any bitterness towards life. This valuechanging gives them another opportunity to live and to take care of the rest of their lives.

Surrendering mode

In the surrendering mode, patients and relatives are surrendering themselves to a life on hold through total trusting, releasing control, and evaluating. Two main reasons for being in the surrendering mode are attitudes of resigning or accepting. Resigning means that they have given up and they surrender to a life on hold. They have tried fighting or even tried adjusting to a life on hold, but lack of motivation or energy has left them without a sense of meaning, so they surrender. Accepting means surrendering by submitting their lives to a higher power; to God or to destiny. *If I am meant to survive, I will survive, otherwise I will die and that's it.*

Total trusting

Total trusting means living in complete trust that everything is going to be alright. Through surrendering their lives and responsibilities into the hand of others, patients and relatives can relax and experience a total trust. It is easier when being in this mode is caused by an accepting rather than a resigning attitude. Resigning takes more time to fully trust others. Trusting makes living on hold bearable while distrust makes it intolerable. It is therefore important that professionals are promise keepers; otherwise waiting will lead to distrust. Even if they have released the control and do not question the care, patients and relatives appreciate anticipatory care, since it foresees problems that can be solved and it ensures trust. They do not mind hearing about what might happen, but they do not want to be involved; they surrender to others to resolve issues. They see the situation as a waiting period and finally accept living in a world of waiting. By a wait-and-see strategy, they take life as it comes facilitated by total trusting. So total trusting can lead to increased satisfaction and a feeling that everything is going to be alright.

Releasing control

By releasing control, patients and relatives are letting go of controlling normality and surrendering themselves to an unknown situation. This is easier when the surrendering mode is caused by accepting rather than by resigning, and when releasing control is facilitated by total trusting. They do not need to be in control anymore and they literally put their lives into the hands of others. So patients can submit control to relatives, as well as relatives can submit control to patients, but most common is that control is submitted to health professionals who are supposed to take control. In submitting control, no involvement or participation in the care is wanted since they are totally trusting that professionals know what is best for them and that everyone wants their best. Being in the hands of others can be both good and bad. By releasing control some think that they give up their rights to complain, question or doubt treatments, tests or the care. This can be caused by a fear of being abandoned if they question the care but also a fear of being a burden to people around them. But through pleasing, they decrease this risk of being abandoned and they feel safe and secure again.

Surrendered evaluating

Evaluating involves accepting the situation and preparing for death. This can be more difficult if the reason for being in this mode is resigning. It then takes longer to accept and they might experience bitterness through the evaluating life process. Through accepting the situation they value their lived life. They are either contented with how life turned out and therefore accept the situation or they finally accept their situation by resigning. They do not want to complain or ask for more in life, because it would be an assault to life itself or to God himself. Despite being satisfied with their lives or feeling that they do not have anything more to live for, they mourn the life that they are going to leave. Through mourning life, they are preparing to face death, trying to imagine the time until death, comforted by the faith that everything will be alright. Relatives in this mode may prepare both for the patient's death but also for their own future death.

Feasible mode shifting and possible outcomes

Mode shifting can happen anytime during a trajectory through the reconciling process. As mentioned before, the patients and their relatives can either be in the same mode or in different modes simultaneously. This mode synchronicity can lead to problems and conflicts within the family but also in contact with health professionals. Modes are sometimes not totally separated from each other; there can be a mode mix when two modes overlap and individuals use strategies from two modes at the same time. Table 2 shows how complicated a situation can be but it can be even more complex when there is more than one relative involved. The easiest situation for everyone involved is when patients and relatives are in the same mode, reducing the risk of conflicts and misunderstandings within the family and with professionals.

Young patients and relatives want more anticipatory caring and they are more often in the fighting mode than older persons. Here again, there can be problems and conflicts when patients and relatives are in different modes. For example, when a patient has run out of energy to keep fighting and goes from the fighting mode to the surrendering mode, but the relatives still are in the fighting mode and want to keep on fighting, it is not only a problem for the family but it can also be a problem for the professionals in their communication with the family. They need to meet the family at different levels and need to be aware of patients' and relatives' mode being.

Table 2: Possible outcomes of being in the different modes

		Relative		
		Fighting	**Adjusting**	**Surrendering**
Patient	**Fighting**	Ok within the family	Risk for conflicts	Risk for conflicts Vicarious fighting
	Adjusting	Risk for conflicts	Ok within the family	Risk for conflicts
	Surrendering	Risk for conflicts Vicarious fighting	Risk for conflicts	Ok within the family

In the fighting mode, patients or relatives can feel that there is nothing more to fight for, and that they are fighting a losing battle. This can be triggered by new uncontrolled symptoms and they may sense that there are no more things to change so they transfer over to the adjusting mode and try to create a new normality so as to live life as normally as possible. One outcome of the reconciling process, however, can be that they have no energy left to fight and they give up and transfer over to the surrendering mode. Being in the adjusting mode can move a patient or relative back to the fighting mode if the care is failing, and this is signalled by incidents that trigger such a move. But it seems rare to change from the surrendering mode over to the fighting mode or the adjusting mode, since surrendering seems more final. The adjusting mode can be more difficult to be in than the surrendering mode. Patients in particular have more difficulties to adjust than relatives, while relatives have more difficulties to accept the situation and surrender than patients.

Vicarious fighting means that someone is taking over the fighting from another person. So, if one person does not have the energy to stay in the fighting mode, another person can step in and be a vicarious fighter. The strategies are almost the same as in the fighting mode, but the blaming strategy is not often used during vicarious fighting. Vicarious fighting can become a permanent mode if the person is motivated to keep fighting. Some patients and relatives are in the fighting mode during the whole trajectory and never stop fighting. Even after the patient's death, relatives can still fight to find answers and eventually find someone or something to blame.

Discussion

In this grounded theory we found that the main concern for palliative cancer patients and their relatives in home care is that their normal lives are being put on hold. Living on hold emerged as the pattern of behaviour through which they deal with their main concern. Living on hold involves three behaviour modes: Fighting, Adjusting and Surrendering. The actual mode being depends on variables that change over time. Thus, mode being can change during a trajectory caused by triggers that start a reconciling process leading to a possible mode change. Mode synchronicity can vary for patients and relatives, and this can cause problems and conflicts within the family, and in interacting with health professionals. Living on hold does not represent patients' and relatives' entire doing or being, but is one important pattern of behaviour in which they are engaged. A grounded theory is abstract of time, place and people (Glaser, 1978, 1998) and with this in mind, Living on hold might well be expanded to other areas to contribute to understanding how people are living on hold in different situations and contexts. Further research is needed to determine if the theory fits other substantive areas and where new concepts could emerge to modify the present theory to optimize the fit.

The concepts “putting on hold” and “a life on hold” have been used and described earlier in different contexts with various definitions. A life on hold was used to describe the situation for homeless families (Sawtell, 2002) and putting life on hold was used when discussing the duration of hypothermic arrest in a clinically relevant trauma model (Alam, et al., 2008). Being put on hold has several similarities with studies describing experiences for people involved in palliative care with uncertainty being common in patients and relatives, but also in health professionals (Appelin, Broback, & Bertero, 2005), and living without normal time references has been described as frustrating (Sand, et al., 2008).

Fighting, adjusting and surrendering are not new concepts. The fighting mode could be compared to fighting as explained by Jussila (2008) and Pergert (2008). The adjusting mode is similar to “living as usual”, where maintaining independence and integrity were important (Bertero, Vanhanen, & Appelin, 2008), “keeping things normal or as normal as possible” (Thomas, et al., 2002), “adjusting to life with the disease” (Jussila, 2008) and “striving to adapt oneself to the situation” (Eriksson & Andershed, 2008). There are also elements of denial in the adjusting mode that resembles “disavowal” (Salander & Windahl, 1999). Surrendering could in some part be compared with submitting explained by Jussila (2008).

Health professionals need to be aware that patients and relatives can go through the reconciling process many times with possible mode shifts as a consequence. These mode shifts can happen when least expected and can affect the whole situation more than they themselves or the professionals can imagine. Our study shows that patients and relatives are hypersensitive to everything that happens around them. This hypersensitivity can lead to positive changes in the care, but most of the time, the hypersensitivity is energy draining. Health professionals need to be aware of the patients’ and relatives’ hypersensitivity and facilitate their lives on hold through decreasing the factors and triggers causing hypersensitivity. For example, uncontrolled symptoms are one kind of trigger and Block (2001) suggests that controlled symptoms increase the possibility to address patient concern about their families and about finding meaning in their lives. This is also seen in our study, where controlled symptoms increase the possibility for patients to stay in their mode being. Also the professionals' behaviour can alleviate the unnecessary uncertainty and unrealistic fear of what might happen, underpinning feeling in control and decreasing hypersensitivity. Further research is needed to explore more about the reconciling process, its consequences and what triggers it.

Professionals are supposed to give individual care, but this can be difficult when patients and relatives are in different modes with apparently different needs. Awareness and knowledge of the different modes may facilitate care giving and support at the right level for each person in the family. Eriksson, Arve and Lauri (2006) emphasize the importance of patient authorization before passing on information to relatives. So, if the patients do not want to share their situations with relatives, professionals are in a difficult position, knowing what might be best for the relatives but unable to support them. Professionals act through different caring behaviours such as anticipatory caring (e.g. through foreseeing trajectories), momentary caring (e.g. through temporarily prioritizing) and stagnated caring (e.g. through resigning) (Sandgren, Thulesius, Petersson, & Fridlund, 2007) and these different behaviours may clash with the different modes which patients and relatives are engaged in to handle a life on hold. Anticipatory caring aligns with the fighting mode because persons in this mode want to foresee what will happen and be prepared for what might happen. On the other hand, momentary caring aligns well with patients and relatives in the adjusting mode, since they want to live in the moment and momentary caring involves problem solving when problems arise. However, there can be conflict when professionals want to give anticipatory care and patients and relatives are in the adjusting mode façading their wish to live as usual. Façading can be used within the family but also in interaction with professionals. Pergert (2008) suggests that façading is used to protect oneself and/or others, and this strategy can be used by patients and relatives but also by professionals to protect from overwhelming emotions. Façading could also be compared with professional shielding, where nurses use their profession as a shield to protect themselves emotionally (Sandgren, Thulesius, Fridlund, & Petersson, 2006). For professionals it is easier to give individual care when patients and relatives are in the same mode struggling together towards the same goal. This was shown by Thomas et al (2002) who describe a struggle of companions through the cancer trajectory.

Since patients and relatives can be in the same or in different modes, an increased awareness is needed in meeting their different needs. This is in line with Faulkner and Maguire (1994), who point out that patients and relatives can have different perspectives on the situation, and further on these different perspectives are exhibited as rival needs. There is often reluctance to disclose needs to professionals (Ramirez, et al., 1998) perhaps due to fear of being abandoned (Eriksson & Andershed, 2008). Being in different behaviour modes can entail different perceptions of the health professionals. There are unspoken expectations on how to behave and act (Thomas, et al., 2002) and this may lead to increased stress, both physical and emotional. O'Baugh et al. (2003) found that nurses' perceptions of positive patients were those who followed orders and did what they were supposed to do. Negative patients were those who were demanding and wanted everything scheduled around their lives. This could be compared to our study with patients and relatives being in the fighting mode where they can be perceived as demanding and impatient. Yet, this can be something positive for them, since they are trying to regain normality and wanting to participate in the care. On the other hand, persons in the surrendering mode are often perceived as positive since they have let go of the control and submitted to professionals to decide what is best for them. They are following directions and are seen as good patients and good relatives. However, patients and relatives in the surrendering mode might need support and encouragement the most. It is therefore important to acknowledge the professionals' attitudes since they can affect care negatively. Furthermore, it must be emphasized that no mode is better than another, neither from the patients' and relatives' view, nor from the health professionals' perspective. There are advantages and disadvantages with being in all the modes, and it can be more or less easy for professionals to meet the patients and relatives at the right level, depending on their own caring behaviour and attitudes. But with knowledge and awareness of patients' and relatives' different mode behaviours and their own caring behaviours, health professionals will have a more solid foundation when giving palliative care.

Conclusion

The theory Living on hold explains how palliative cancer patients and their relatives handle their lives being put on hold. This involves the behaviour modes Fighting, Adjusting and Surrendering. Mode synchronicity can vary for patient and relatives, and this can cause problems and conflicts within the family, or with health professionals. It is therefore important for health professionals to be aware of what modes patients and relatives are in to be able to meet, communicate and support them at the right level. Although the theory emerged from home care data, Living on hold may contribute to a general understanding of how people deal with their lives being put on hold. Further research may elaborate how health professionals with their different caring behaviours can give optimal care to patients and relatives in different behaviour modes.

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