

Complexities in Palliative Cancer Care: Can Grounded Theories be Useful to Increase Awareness?

Anna Sandgren, Linnaeus University, Sweden

This paper includes first a summary of a grounded theory "Living on hold", which was one of four different grounded theories in my dissertation (Sandgren, 2010). The theory is then explained in relation to the other grounded theories to give an example of how different grounded theories can be integrated, which leads to an increased awareness of what is going on in a research area.

Keywords: palliative cancer care, increase awareness, grounded theories, living on hold.

Living on hold

The aim of this study was to develop a classic grounded theory of palliative cancer patients and their relatives. Interviews and data related to behavior of patients and relatives were analyzed.

Being put on hold emerged as the main concern for palliative cancer patients and their relatives. Being put on hold means that their normal existence is falling apart; normality is breaking down and with it a loss of control. Living on hold consists of three modes of behaviors: the fighting mode, the adjusting mode, and the surrendering mode. Mode being, an individual's current mode, depends on, for example, age, personality, diagnosis and prognosis, social network, earlier experience of crisis, continuity of care, and professional competence. During the disease trajectory, there may be triggers that start a process of reconciliation that can lead to mode shifts, so modes are not fixed. No mode is better than another.

The process of reconciling

Regardless of mode, patients and relatives evaluate not only their lives and their current situation, but also the past and the near future. Mode shifting can happen at anytime during the disease trajectory through the reconciling process. Mode shifting triggers, such as receiving bad news, dependency experience, and feelings of uncertainty, can trigger the reconciling process and lead to a change in behavioral mode. Patients and relatives often evaluate life differently, which may lead to individuals experiencing different behavioral modes within a patient's group. Depending on their different moods, shifting between modes can happen quickly over a short period of time, which could be energy draining for all involved.

Fighting mode

In the fighting mode, patients and relatives are striving to renormalize their lives; no

change to their previous way of life is desired. Through renormalizing, they strive to return to normal, managing themselves, and keeping track as before. Potential powers are discovered and unrealized innate powers may emerge when needed. Rebellious means not only protecting and fighting the whole situation, but also fighting the disease. Through blaming, patients and relatives seek reasons or causes for the disease, and finding something or someone to blame. In the fighting mode, they appreciate foreseeing, since this gives them full control over life, even if it is put on hold. Since individuals are hyper-sensitive, they are scrutinizing everything around them.

Adjusting mode

In the adjusting mode, patients and relatives are adjusting to a new normality and to new routines. Even though they are adjusting, they do not let the disease take over or control their lives. Adjusting to a life on hold involves moment living, which means maintaining a total presence here and now and involves planning for daily life but not for the future. Disease diminishing, which means not letting the disease affect their lives, is achieved through re-routining where new routines are created. Adjusting also involves façading, which means keeping an emotional facade and staying emotionally strong.

Surrendering mode

There are two different ways of being in the surrendering mode: resigning, which means giving up, or accepting, which means submitting their lives to a higher power. In surrendering mode, a life on hold is handled through total trusting. Individuals live in complete trust that everything is going to be alright and they have full trust in others to make decisions. Through releasing control, they let go and surrender control to the health professionals and do not seek any participation in the care.

Feasible mode shifting and possible outcomes

Patients and relatives can be either in the same or in different mode simultaneously; this mode synchronicity may lead to problems within the family and also when in contacts with health professionals (Figure I).

Relative

	Fighting	Adjusting	Surrendering
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	Risk for conflicts	Ok within the family

Patient		fighting		
----------------	--	----------	--	--

Figure I. Possible outcomes of being in different modes for patient and relative

Complexities in palliative care

The situations for health professionals, patients and relatives in palliative care are often complex. To explain some of these complexities, the theory Living on hold will be integrated with the theories Doing good care, Striving for emotional survival, and Deciphering unwritten rules.

The grounded theory Doing good care explains how nurses can have different caring behaviors i.e. anticipatory caring (doing best or even better than necessary through foreseeing trajectories, creating trust, collaborating and prioritizing); momentary caring (doing best momentarily as well as possible in every situation through temporary solutioning and sporadically collaborating); or stagnated caring (doing what is expected of them through avoiding changes and resigning) (Sandgren, Thulesius, Petersson, & Fridlund, 2007). There can be tensions and clashes when professionals have these different caring behaviors and they then meet patients and relatives who are handling their lives being put on hold through the different modes: fighting, adjusting, and surrendering (Sandgren, Thulesius, Petersson, & Fridlund, 2010). For example, if professionals are using anticipatory caring behaviors and the family is in the adjusting mode, displaying facading and moment-living behaviors, the family may not act or behave as if they have understood the information about the seriousness of the situation and the potential for a terminal outcome for the patient. The family lives on as usual, confusing the professionals who give the same information over and over again to try to make the family understand the situation. This leads to frustration for all involved; the professionals may feel that they are not giving the “right care” and are letting the family down. The family, on the other hand, may feel disrespected and trodden on. Professionals’ assumptions of what seems to be the best for the patient may actually be in conflict with the patient’s wishes. For instance, professionals often perceive patients and relatives in the surrendering mode as positive. The professionals decide what seems to be best for the patients and relatives, without even asking them. They are then seen as good patients and good relatives since they follow all the directives whereas, in fact, patients and relatives who are in the surrendering mode might be the ones who are the most in need of support and encouragement.

In the grounded theory deciphering unwritten rules, the main concern for everyone involved in palliative care is struggling with how to act and behave (Sandgren, 2012). This affects not only how health professionals give care and survive emotionally (Sandgren, Thulesius, Fridlund, & Petersson, 2006), but also how patients and relatives experience the care. For example, nurses engaged in stagnated caring behavior and patients and relatives in the surrendering mode may not have the emotional sensitivity to figure out the unwritten rules of how to act and behave. Instead, they are passing over, which means they are leaving other people around them to figure out the rules, and then copying and following their behavior. However, nurses engaged in anticipatory caring

behavior are on the other hand figuring out the rules in an active way, the same way as patients and relatives in a fighting mode do. When patients and relatives are lacking information and support, they are finding out how to act in order to obtain what they need (Sandgren, 2012).

Methodological notes

In order to explain the complexities in palliative care, four grounded theories were integrated. Analysis was done on earlier written memos and the theories. New conceptual memos were written (Glaser, 1998) about how the theories could be integrated to explain the complexities. Memos were written about how the mode behaviors and strategies in the separate theories related to each other, possible outcomes, and which consequences these outcomes have for nurses, patients and relatives. These memos were then hand-sorted.

Conclusions

This paper demonstrates the complexities in palliative cancer care that are often not recognized by those involved. The grounded theories in this paper can be used to increase awareness and understanding about these complexities, which may positively affect how the care is given and how the care is perceived by the patients and relatives.

References

- Glaser, G. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.
- Sandgren, A. (2010). *Deciphering unwritten rules. Patients, relatives and nurses in palliative cancer care*. Dissertation. Linnaeus University.
- Sandgren, A. (2012). Deciphering unwritten rules. *The Grounded Theory Review*, 11(2).
- Sandgren, A., Thulesius, H., Fridlund, B., & Petersson, K. (2006). Striving for emotional survival in palliative cancer nursing. *Qualitative Health Research*, 16(1), 79-96.
- Sandgren, A., Thulesius, H., Petersson, K., & Fridlund, B. (2007). Doing good care – a study of palliative home nursing care. *International journal of Qualitative Studies on Health and Well-being*, 2(4), 227-235.
- Sandgren, A., Thulesius, H., Petersson, K., & Fridlund, B. (2010). Living on hold in palliative cancer care. *The Grounded Theory Review*, 9(1), 79-100.