

Deciphering Unwritten Rules

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Abstract

The aim of this study was to develop a classic grounded theory of patients, relatives and nurses in palliative cancer care. Data from three earlier studies conducted in palliative care were analyzed. "Deciphering unwritten rules" emerged as the pattern of behavior through which patients, relatives and nurses are dealing with the uncertainty of how to act and behave in palliative cancer care. Deciphering means finding out what the rules mean and trying to interpret them and this can be done consciously or unnoticed. Deciphering unwritten rules involves the strategies figuring out, deliberating, maneuvering and evaluating. This theory demonstrates the complexities of palliative care and the importance of knowledge, counseling and resources for all involved.

Introduction

Palliative care is a caring philosophy with the goal to achieve the best possible quality of life for both patients and relatives when facing problems related to life-threatening illness (World Health Organization, 2003). The adjustment and transition to palliative care takes time for patients and relatives, and involves shifting the care goals from curing to caring (Duggleby & Berry, 2005). In the 1960's it was common for patients not to be informed of their impending death; so the awareness of dying among patients and relatives was mostly a closed awareness (Glaser & Strauss, 1965). The pendulum has shifted during the last decades towards open awareness, where those involved talk more about death than they have in the past (Andrews & Nathaniel, 2009).

Powerlessness and helplessness is common in dying patients (Sand, Strang, & Milberg, 2008) who often oscillate between different feelings such as hopelessness and hope (Melin-Johansson, Odling, Axelsson, & Danielson, 2008). So even if patients have a lower quality of life in many dimensions during their last months of life, they can still experience happiness and satisfaction (Sahlberg-Blom, Ternstedt, & Johansson, 2001). For the relatives, the situation is new and they need to make adjustments, although they want to keep on living as normally as possible (Appelin, Broback, & Bertero, 2005; Sandgren, Thulesius, Petersson, & Fridlund, 2010), yet having a twofold role; as caregivers and as relatives suffering anxiety and physical exhaustion (Broback & Bertero, 2003). Both patients and relatives can be hypersensitive to what happens during the dying trajectory and this hypersensitivity is energy draining (Sandgren et al., 2010). It has been shown that adequate information and support from the health professionals early in the disease trajectory decrease relatives' needs throughout the dying trajectory and increases their trust and confidence towards the health professionals (Kristjanson & White, 2002; Wenrich et al., 2003).

Caring for cancer patients can be both challenging and rewarding for nurses (Corner, 2002; Penson, Dignan, Canellos, Picard, & Lynch, 2000) who often want to go beyond the diagnostic concept of cancer and care for the whole person (Bertero, 1999). A balance between being close to the patients and distancing themselves is needed to avoid the risk of

being emotionally overloaded (Sandgren, Thulesius, Fridlund, & Petersson, 2006). Palliative care can also be seen as a balancing act, where health professionals need to balance the needs for care with the resources to give care (Thulesius, Hakansson, & Petersson, 2003). There can be a tension or a gap between nurses' caregiving ideals and the reality of daily work. Nurses can be aware of their ideal of how to give good palliative care, but the possibilities to realize these are often small (Tishelman et al., 2004). To give high quality palliative care, health professionals need to know what is important for those involved. The aim of this study was therefore to generate a grounded theory explaining the latent patterns of behavior of patients, relatives and nurses in palliative cancer care in general hospitals and in homecare. The research question guiding the study was: What is the main concern for palliative cancer patients, their relatives and nurses and how do they resolve it?

Method

Classic grounded theory was chosen since it suited the research question. Grounded theory methodology provides a way to explore the latent pattern of behavior of the participants (Glaser, 1978, 1998) and is suitable for nursing research (Nathaniel & Andrews, 2007).

In this study, the analysis was mostly done using previously collected data. Glaser (1998) argues that secondary data analysis can be used on data collected for other purposes and is worthwhile to theoretically sample and analyze. Grounded theory focuses on conceptualization instead of descriptions which means that the concepts that emerge from the data will transcend the data and make the theory abstract of time, place and people. Glaser stresses that using secondary data is timesaving for the grounded theorist since less time is spent on data collection.

The analytic process started with open coding of data from three earlier grounded theory studies as a basis for concept generation: Striving for Emotional Survival (Sandgren et al., 2006), Doing Good Care (Sandgren, Thulesius, Petersson, & Fridlund, 2007) and Living on Hold (Sandgren et al., 2010). These studies were all related to the behavior of patients, relatives and nurses in palliative cancer care, and were conducted in general hospitals and in home care settings in Sweden between 2004 and 2009. The formal interviews from the three studies were done with 16 nurses in acute care settings (Sandgren et al., 2006), 33 nurses in community care (Sandgren et al., 2007) and 25 cancer patients in a palliative phase and their relatives (Sandgren et al., 2010). During the open coding, focus was on the following questions: What is the main concern being faced by patients, relatives and nurses, and what accounts for the continual resolving of this concern? The purpose of these questions is to keep the analyst theoretically sensitive and to avoid description when analyzing, collecting and coding data (Glaser, 1998). It should be emphasized that data collection and data analysis are not seen as separate processes in grounded theory; rather, as concurrently conducted (Glaser, 1998). When the core category had emerged, the selective coding process began where further data collection and coding were delimited to the categories related to the core category.

Theoretical sampling guided where to collect more data in order to refine and elaborate emergent categories and how the categories related to the core category in the emergent theory. Theoretical saturation occurs when no new properties emerge; the same properties continue to emerge when coding and analyzing the new data (Glaser, 1978). To saturate the emerging concepts, previously conducted interviews in palliative care from both published (Thulesius et al., 2003) and unpublished studies were analyzed. Consistent with the grounded theory concept "all is data" (Glaser, 1998, p. 8), data analyzed consisted of interviews, field notes, memos from informal interviews and participant observations at

cancer care conferences. Casual conversations or unplanned conversations with health professionals and others involved in the substantive area were also used as data for constant comparison. Since the author has worked in cancer care at a surgical ward, the author's experiences and preconceived thoughts were written down and compared with the other data, also in line with the "all is data" dictum (Glaser, 1998).

During the analysis process, memos were written to capture emergent theorizing at any time and place, often in the shape of figures and text to capture creative ideas. Glaser (1998, p. 177) explains that memos are the "theorizing write-up of ideas about substantive codes and their theoretically coded relationships as they emerge during coding, collecting and analyzing data and during memoing". Memoing is seen as foundational in classic grounded theory; without memos there could be no grounded theory. Memos on memos were also written and later on, the memos were then sorted in the theoretical coding process and written up as the theory of deciphering unwritten rules. In the theoretical coding process, relationships between the categories and the core category emerged through the hand sorting of memos.

In accordance with classic grounded theory, the literature review was not undertaken until the substantive theory was formulated. The literature was then used as another source of data for constant comparative analysis (Glaser, 1998).

Ethical issues are important to discuss when using secondary analysis (Andrews, Higgins, Waring, & Lalor, 2012). In this study, all the previous studies included as data were approved by The Regional Ethics Committee of Lund University, Sweden and by responsible managers for the hospitals and the home care in the municipalities involved. Written informed consent was obtained from the participants before the formal interviews. During the secondary analysis all the original transcripts, field notes and memos were anonymized with no possibility of tracing the participants in the different studies.

Theory

Unspoken expectations and unwritten rules of how to behave in different situations exist although nobody talks about them. In different caring contexts, there are various unwritten rules which may entail contrasting types of atmosphere. It can be hard to pinpoint what makes the difference, but one possible explanation is that unwritten rules can create special atmospheres. Unwritten rules can deal with values and attitudes individuals expect to have confirmed or accepted.

The uncertainty of how to act and behave in an appropriate and correct way in different situations emerged as the main concern for nurses, patients and relatives in palliative cancer care. Everybody understands that there are unspoken rules to follow but it can be difficult to learn them since they are continually changing and differ from situation to situation. Not knowing how to act or behave was explained as "struggling against a faceless, invisible giant". Not knowing what was expected of them caused uncertainty that can be exhaustive, creating emotional fear of being unsafe. There is therefore a need for certitude, or creating certainty in an uncertain situation. Handling the uncertainty of how to act and behave therefore requires constantly deciphering the unwritten rules. Deciphering means finding out what the rules indicate and trying to interpret them in actual situations, which can be done consciously but most of the time the rules are deciphered subconsciously.

Health professionals may signal to patients and relatives, wittingly or unwittingly, how they are supposed to behave and what problems are important from the professionals'

perspectives. This influences the interaction regarding what issues they are allowed to talk about or not. One example of deciphering unwritten rules can be how to deal with sensitive issues depending on the persons involved and the actual context. There can be unwritten rules such as: "Don't talk about the problem", "Act like nothing has happened", "Don't say things to upset the ill person", "Don't talk about your feelings and absolutely do not show your feelings in the open", "Open feelings leads to conflict". Deciphered unwritten rules of how to behave could actually lead to decreased instead of increased security for those involved. This insecurity can be regarded as "walking on eggshells" when the individual does not know how to act. The complexity increases when, for example, patients are cared for in different caring contexts with totally different unwritten rules. With fast changes, patients do not have the energy to decipher the unwritten rules, and may surrender with the attitude "do whatever you want to do with me; you know what is best for me".

For nurses, there are also unwritten rules regarding workplace etiquette, which means that nurses are supposed to have certain values or behave in a certain way. There can be an unspoken rule like: "Good is not good enough". This means that as nurses, they need to overdo things to show other professions that they can do what is expected of them and even do better than necessary.

Deciphering unwritten rules is done by patients, relatives and nurses and is necessary for deciding if the rules are to be followed or not. How patients, relatives and nurses decipher unwritten rules depends on their personality and experiences. For nurses, it also depends on their caring behavior, i.e. anticipatory caring, momentary caring or stagnated caring. Anticipatory caring is done by advanced care planning through foreseeing trajectories, creating trust, collaborating and prioritizing. The nurses are driven by their intention of doing their best or even better than necessary. Momentary caring is done by temporary solutioning through moment prioritizing and sporadic collaborating. The nurses are doing as good as possible in every situation but lack the resources to render anticipatory care. Stagnated caring entails avoiding changes and resigning (giving up). Nurses giving stagnated care are doing only what is expected of them which could be caused by resigning or low emotional competence. Emotional competence refers to emotional skills at handling emotionally charged situations (Sandgren et al., 2007).

How nurses decipher unwritten rules can also determine how nurses process their emotions while caring for palliative cancer patients (Sandgren et al., 2006). For patients and relatives, it can depend on their mode of being while living a life on hold; fighting, adjusting or surrendering. Patients and relatives can either be in the same mode or in different modes simultaneously. In the fighting mode, patients and relatives are striving to get back to the normal lives they had before the cancer literally took over. The fighting mode involves renormalizing, rebelling, blaming, foreseeing and scrutinizing. In the adjusting mode, patients and relatives are adjusting to a new normality and try to avoid letting the cancer control their lives. They adjust to the new normal by moment-living, diminishing and façading. In the surrendering mode, patients and relatives are giving up to a life on hold through total trusting and releasing control (Sandgren et al., 2010).

Even though patients, relatives and nurses are deciphering, the strategies used are more or less common. Therefore, some examples are highlighted under the strategies, but it should be emphasized that the persons involved can use all the strategies in the process. Deciphering unwritten rules is a continuous process which involves figuring out, deliberating, maneuvering and evaluating.

Figuring out

Figuring out means finding out which rules are valid and present in novel situations. Figuring out unwritten rules is done when entering a new caring context, meeting new people, when being in a new situation or when experiencing new symptoms. Figuring out the unwritten rules can be experienced as an unattainable goal. Although the rules are unwritten, patients, relatives and nurses have a tacit awareness of the existing rules, but since this shared awareness is not communicated verbally, unwritten rules may be taken for granted and therefore easily missed by someone new to the situation. Ruminating over how to act and behave can paralyze the involved persons and decrease their ability to figure out the unwritten rules, which can be done in an active way or in a passive way.

Figuring out in an active way

Figuring out the rules in an active way is done through moment capturing and constantly questioning. Moment capturing means every opportunity is taken to figure out the unspoken rules. Constantly questioning the care is a way to handle the insecurity of not knowing the unwritten rules. Through questioning, patients, relatives and nurses get attention from the people around them which may lead to a disclosure of the unwritten rules. The purpose of deciphering unwritten rules is important when figuring out the rules in an active way. For example, patients and relatives in the fighting mode may experience insecurity when lacking information and support, but with knowledge of the unwritten rules they can find out how to act to get what they need. A genuine desire of doing good helps nurses engaged in anticipatory caring to figure out which unwritten rules are useful to get them what they want. Both at a personal level but also when giving palliative care.

Figuring out in a passive way

Figuring out in a passive way is done through passing over or acting incompetent. Passing over means letting other people figure out the rules. Nurses engaged in stagnated caring and patients and relatives in the surrendering mode may not have the emotional sensitivity to figure out the rules by themselves. Instead, they let those around them take that responsibility and then copy and follow their acting. Passing over is easier for patients and relatives than for nurses, although it is possible to pass over during a short period of time without impacting the care.

Acting incompetent is a way to passively figure out the rules. Even though participants may have the ability to figure out the rules in an active way, it is more convenient to be passive and act incompetent. Being in the adjusting mode for patients and relatives leads to insecurity of not knowing how to act and since they do not want to show their vulnerability, they act incompetent to figure out the rules. From a professional perspective, patients and relatives seem to deny the situation, which can be difficult for professionals to handle. Nurses also act incompetent to receive help in disclosing unwritten rules in order to get what they need from the situation.

Deliberating

After figuring out the unwritten rules, patients, relatives and nurses deliberate as to how these rules might affect their situation and how they will act in relation to the rules. They consider which rules to apply to receive the best outcome from their point of view and there can be different reasons for this deliberating. Patients and relatives might deliberate how to act to get the treatment they want or receive the "right" care for the moment.

Inability to deliberate could be caused by lack of energy, lack of knowledge or low motivation, but insecurity and low emotional competence also affect how the involved deliberate the rules. Being in the fighting mode motivates patients and relatives to deliberate the rules in their favor since knowing the rules and how to handle them increases

their feeling of security. On the other hand, patients and relatives in the surrendering mode are not active in deliberating which rules to apply; they just follow the people around them and hope for the best. Acting incompetent can also be used when deliberating the optimal way of dealing with the rules.

Deliberating which rules to apply or not can be affected by dual protection in a family. Dual protection means a relational security: "I will be okay if you will be okay". Deliberating can also be affected by patients' posthumous caring, which means protecting by taking care of what will happen to the relatives after the patient's death. This includes financial and practical issues to secure the family's future. Patients therefore deliberate which rules to apply to be able to reach their goals.

Before deciding which rules to apply, the rules may be tested to find out if they have been deciphered correctly and if they are good to follow or not. Nurses in momentary caring are often testing consequences of newly deciphered rules in specific situations. They are moment-prioritizing which means that they are solving a problem when it arises and under the circumstances doing their best.

Maneuvering

After deliberating, patients, relatives and nurses maneuver the rules by either following rules, ignoring rules, rebelling against rules, rule bending, rule breaking or rule making.

Following rules

The decision to follow unwritten rules may depend on the anticipated positive benefits of acting by the rules. Some rules are, from a personal perspective, good to follow while other rules may not be so good. Yet, the outcomes are more important than the rules themselves so sometimes patients, relatives or nurses feel forced to follow the unwritten rules to be able to get what they want out of the situation. Although the rules may give the expected outcome, there is a risk of losing one's own values and attitudes when complying with new rules. Having high emotional competence facilitates deciding which rule to apply in any given situation. Through façading, they pretend to follow the rules, but instead they collect clues of how to decipher the unwritten rules by observing how others behave and copying their behavior. By façading, patients, relatives and nurses maintain the image of knowing and following rules, even though they have not figured out the meaning of the rules. There is a constant emotional fear of breaking rules and of the consequences of rule breaking. This fear might increase among patients and relatives who want to do everything as expected, and not causing any problems for the health professionals.

Not everyone has the ability to decipher unwritten rules and patients and relatives can become insecure as how to interpret them. Also, if patients, relatives and nurses disclose their ignorance of how to act by showing vulnerability and insecurity, they may lose their façade, leading to feelings of failure.

Ignoring rules

Ignoring rules is used as an emotional protection and may be caused by problems with deliberating rules. Since they do not understand the meaning of the rules, it is easier to deny them than to try and decipher them. Pretending that the rules do not affect them, patients, relatives and nurses can live their lives as usual for as long as possible. Patients or relatives, who have been disappointed in earlier situations, may ignore rules to protect themselves from being emotionally hurt again. Patients and relatives in the adjusting mode may seem to deny unwritten rules since they do not act as expected, even though they often suffer in silence. Ignoring rules is common among nurses in stagnated caring, since they do not want any changes. Nurses in both momentary and stagnated caring may ignore

rules when they experience new situations and have to learn several things at the same time.

Rebelling against rules

If the unwritten rules do not fall in line with personal values, an individual may rebel against the rules. Patients and relatives in the adjusting mode may choose to rebel against the rules rather than ignore them. Rules regarding how to act towards the end of life might be upsetting for patients and relatives. When they do not accept that death is inevitable, they may rebel against these rules.

When nurses use anticipatory caring, they may rebel against rules that go against their values and the goals of palliative care. Since they want to be one step ahead, there might be unwritten rules hindering this approach. Rebelling against rules may lead to rule bending and later on to rule breaking. Also, nurses in stagnated caring may rebel against the rules; this is often due to incompetence and lack of knowledge as to how to maneuver new rules. In such cases, it is more convenient to follow ingrained rules.

There can also be a rebelling against working etiquette rules for nurses. One provocative unwritten rule could be: "Nursing is a mission in life and you must be a 'Nightingale sister' and sacrifice yourself if you want to work here". This unwritten rule can be upsetting and nurses openly rebel against it through rule breaking which then leads to rule making to change this provocative unwritten rule.

Rule bending

As mentioned, rebelling against rules might lead to rule bending. Sometimes the rules are bent as much as possible to get what is wanted without breaking the rules. There might also be ways around the rules and by bending the rules, they can indirectly follow the rules but in a somewhat devious way.

By sweetening up nurses, patients and relatives bend the rules to get more attention and receive wanted recognition and the expected care. Sweetening up means that they use flatteries and praise to get what they want. While recognizing that sweetening up nurses, may not be the best way to maneuver the rules, they see it as necessary to receive the outcomes they want in a specific situation.

Rule breaking

Rule breaking can be a consequence of rule bending where patients, relatives or nurses have tried to follow the rules by bending them, but they have realized that it is impossible to continue bending. Both nurses in anticipatory caring and stagnated caring use this strategy, but for different reasons. Nurses in anticipatory caring are rule breaking with the intention of making new rules, while nurses in stagnated caring are rule breaking because they do not have the emotional competence to decipher the rules. For both patients and relatives as well as for nurses, rule breaking may lead to rule making, where new rules are created in order to receive expected outcomes or to give good quality care.

Rule making

Rule making and rule inventing may occur when situations are affected by a lot of changes. Unwritten rules change just like written rules but with unwritten rules, it is unknown who made them and therefore there is no one to blame for the rules. Rule making can threaten to change the atmosphere of a workplace since new rules at first increase the uncertainty until everybody has deciphered the new rules. Nurses in anticipatory caring may create new rules or recreate old ones so that they fit their intentions and ambitions with the care. These new rules may lead to frustration for other nurses and if they do not have the ability or the

energy to decipher these new rules, they may resign to stagnated caring where they ignore the new rules or they may even change workplace in order to find an emotionally safe workplace with rules they can maneuver.

Patients and relatives in the fighting mode may create new rules if they cannot decipher the existing rules, or if they do not receive the expected outcomes. New situations with new rules may also lead to a possible change of mode being for patients and relatives.

Evaluating

Patients, relatives and nurses are continually evaluating their maneuvering of unwritten rules and its consequences. Evaluating means assessing the outcomes from the maneuvering strategies. When evaluating the maneuvering of rules, they may discover that the chosen maneuvering strategy did not deliver the outcomes they expected, and they may therefore deliberate to change the maneuvering of the rules. If nurses in stagnated caring have ignored rules in order to avoid changes later discover that this strategy does not protect them emotionally, they may have to figure out the rules to find another way to maneuver them in order to survive emotionally. Even though those involved may be unaware of the unwritten rules, these rules underpin how they act and make sense of the situation. Although some rules seem irrelevant from an outside perspective, these rules help in navigating the situation. Unwritten rules also help those involved to find their place and to feel safe in the situation, even though it was not their decision to be there since they did not have any other option.

When a situation changes or something unexpected happens, patients, relatives or nurses may need to decipher the new unwritten rules and the deciphering process then starts again. This process is often continuous since there always seems to be new unwritten rules to decipher, triggered by new symptoms or changed symptom burdens, health professionals' acting, new routines, change of hospital ward for patients or a new organization, etc.

Discussion

Grounded theory provided a way to explore the latent pattern of behavior of patients, relatives and nurses in palliative cancer care. Deciphering unwritten rules emerged as the pattern of behavior through which they deal with their main concern; how to act and behave in palliative cancer care. Deciphering unwritten rules can be done in different ways, depending on personality, experiences and the situation.

In this study, secondary analysis was used on previously collected data. Andrews et al. (2012) identify several challenges of secondary data analysis. For example, identifying the main concern may take a long time and require a lot of coding and recoding. Identifying the main concern in this study did not take a long time, which can be explained by the large amount of interviews and detailed field notes which were included as data. When using secondary analysis, theoretical sampling can also be a challenge if the researcher has no possibility to collect new data to saturate the concepts. However the researcher can move back and forth between the existing data and theoretically sample for ideas and concepts that emerge (Andrews et al., 2012). In this study, theoretical sampling was done through collecting more data from previous studies and through informal interviews with nurses and casual conversations with persons involved in palliative care.

It should be emphasized that the theory Deciphering Unwritten Rules does not represent patients', relatives' and nurses' entire doing or being, but is seen as one important

pattern of behavior in which they are engaged. Further research is needed to saturate and fully develop this theory and the impacts of its different strategies. Although the theory might well be expanded to other areas to contribute to an understanding of how people are deciphering unwritten rules in different situations and caring contexts, to determine if the theory fits other areas, further research is needed to modify the present theory to optimize the fit.

The concept unwritten rules has been previously used and described but with various definitions in different areas, such as in pediatric care (Sorlie, Jansson, & Norberg, 2003), family therapy (Feinauer, Larson, & Harper, 2010) and depression in primary care (Wittink, Barg, & Gallo, 2006). So unwritten rules not only exist in palliative cancer care; they exist everywhere and are a consequence of the values and attitudes of the people involved. Mason (2007) suggests that unwritten rules can be life sustaining, but can also be distressing when nurses feel that they are not acting as they are supposed to act, due to unit values or expectations from the staff.

Wengstrom and Ekedahl (2006) point out the importance of understanding and interpreting the hidden codes and the unattainable goals, otherwise professional identities will not be clear when the codes are indistinct. The deciphering unwritten rules theory can therefore help professionals to develop their professional identities through knowledge of how to maneuver the rules. Although health professionals need to be aware of the existence of unwritten rules, they also need to assist new professionals in the workplace to be able to decipher the rules. Health professionals may assume that they talk and refer to the same thing when caring, but actually they have different definitions and attitudes and in reality they are not referring to the same thing at all. Mason (2007) suggests that in some workplace cultures new nurses can be ignored and offered little guidance as to what is expected of them. The new nurses have to learn the rules of the game by themselves and this can be utterly demoralizing. Wengstrom and Ekedahl (2006) argue that when nurses understand the codes and routines in the workplace, it diminishes the risk of changing workplaces.

Deciphering unwritten rules shows that rules and codes may help nurses to work, but they have to be clear and articulated. Nurses can, as time goes by, decipher the existing rules at their workplace and learn the new rules which are constantly being created. On the other hand, patients and relatives have a more complex situation since they have to decipher unwritten rules in more than one context. Patients are often cared for in different caring contexts during a disease trajectory; for example, their own homes, nursing homes, acute care hospital wards and palliative units. During this time, they meet health professionals with different caring behaviors. Since every caring context has its own set of unwritten rules, patients and relatives constantly need to figure out how to act and behave by deciphering the unwritten rules and then remembering which rules are valid in what specific context.

An earlier study shows that families may experience that they are "reinventing the wheel" when they struggle with the same issues as many other families (such as administrative and logistical needs), but lack the knowledge of how to handle them (Rabow, Hauser, & Adams, 2004). Unspoken expectations may affect those involved in different ways (Thomas, Morris, & Harman, 2002; Wengstrom & Ekedahl, 2006). Health professionals may for example signal to patients and relatives what is permissible to talk about and what is not, but they cannot then decipher the responding signals. It was found in an earlier study that physicians wittingly or unwittingly signaled to patients how their emotional problems would be addressed (Wittink et al., 2006). For example, if professionals do not ask about patients' and relatives' needs or preferences, the care will be professional-centered rather

than patient-centered (Widmark-Petersson, von Essen, & Sjoden, 2000). It has been argued that mismatched perceptions may affect the caring relationship as well as the quality of care (O'Baugh, Wilkes, Luke, & George, 2003). With this in mind, it is crucial to ask rather than assume what patients and relatives find important. Giving information and having good communication at the appropriate levels can assist all who are involved in figuring out and deliberating which rules are to be followed.

This theory demonstrates the complexities in palliative cancer care, often unrecognized by those involved. Health professionals need to assist all who are involved to be able to decipher the rules and make invisible rules visible by being sensitive to what patients and relatives want to know. For example, if patients and/or relatives are in a surrendering mode, where they have resigned or surrendered and do not want any participation in the care (Sandgren et al., 2010), it can be frustrating for nurses with an anticipatory caring behavior, where they want to be one step ahead and involve the patients and the relatives in the care (Sandgren et al., 2007). It can create clashes between health professionals and patients or relatives as well as within families if there are different behavioral modes with different abilities to decipher the unwritten rules.

For nurses, frustration can result when colleagues do not want to follow the rules and become rule breakers or perhaps start to create new rules. Depending on the attitudes and the allowance of rule breakers and new thinkers, a nurse may have difficulties being accepted which can lead to insecurity and finally a change of workplace in order to survive emotionally (Sandgren et al., 2006). It is therefore important to make unwritten rules visible, not taking anything for granted or assuming that everybody involved knows about such rules. This can be done through open dialogues at the workplaces and through creating open atmospheres where it is allowed to disclose the unwritten rules.

Conclusion

The theory of Deciphering Unwritten Rules explains how patients, relatives and nurses in palliative cancer care handle the uncertainty of how to act and behave in different situations. They are continually deciphering unwritten rules and the different ways they deal with these unwritten rules affect not only their experiences but also the quality of care. It therefore seems important to uncover the unwritten rules and talk about them. Security may increase when the unwritten rules turn into spoken rules and all involved know what is expected of them. How to facilitate the deciphering for everybody involved in palliative cancer care is indeed a call for future research. This theory may well fit other substantive areas, after some modification, thereby contributing an understanding of how people are deciphering unwritten rules in different situations and caring contexts.

References

- Andrews, L., Higgins, A., Waring, M., & Lalor, J. (2012). Classic grounded theory to analyse secondary data: reality and reflections. *The Grounded Theory Review*, 11 (1), 12-26.
- Andrews, T., & Nathaniel, A. K. (2009). Awareness of dying revisited. *Journal of Nursing Care Quality*, 24(3), 189-193.

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- Appelin, G., Broback, G., & Bertero, C. (2005). A comprehensive picture of palliative care at home from the people involved. *European Journal of Oncology Nursing*, 9(4), 315-324.
- Bertero, C. (1999). Caring for and about cancer patients: identifying the meaning of the phenomenon "caring" through narratives. *Cancer Nursing*, 22(6), 414-420.
- Broback, G., & Bertero, C. (2003). How next of kin experience palliative care of relatives at home. *European Journal of Cancer Care*, 12(4), 339-346.
- Corner, J. (2002). Nurses' experiences of cancer. *European Journal of Cancer Care*, 11(3), 193-199.
- Duggleby, W., & Berry, P. (2005). Transitions and shifting goals of care for palliative patients and their families. *Clinical Journal of Oncology Nursing*, 9(4), 425-428.
- Feinauer, ID., Larson, JH., & Harper, JM. (2010). Implicit family process rules and adolescent psychological symptoms. *The American Journal of Family Therapy*, 38(1), 63-72.
- Glaser, B. G. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying* (2nd ed.). N.Y.: Aldine Publishing Company.
- Kristjanson, L. J., & White, K. (2002). Clinical support for families in the palliative care phase of hematologic or oncologic illness. *Hematology/Oncology Clinics of North America*, 16(3), 745-762.
- Mason, D. J. (2007). On our shoulders. *The American Journal of Nursing*, 107(9), 11.
- Melin-Johansson, C., Odling, G., Axelsson, B., & Danielson, E. (2008). The meaning of quality of life: Narrations by patients with incurable cancer in palliative home care. *Palliative & Supportive Care*, 6(3), 231-238.
- Nathaniel, A. K., & Andrews, T. (2007). How grounded theory can improve nursing care quality. *Journal of Nursing Care Quality*, 22(4), 350-357.
- O'Baugh, J., Wilkes, L. M., Luke, S., & George, A. (2003). 'Being positive': perceptions of patients with cancer and their nurses. *Journal of Advanced Nursing*, 44(3), 262-270.
- Penson, R. T., Dignan, F. L., Canellos, G. P., Picard, C. L., & Lynch, T. J., Jr. (2000). Burnout: caring for the caregivers. *Oncologist*, 5(5), 425-434.
- Rabow, M. W., Hauser, J. M., & Adams, J. (2004). Supporting family caregivers at the end of life: "they don't know what they don't know". *JAMA: the Journal of the American Medical Association*, 291(4), 483-491.
- Sahlberg-Blom, E., Ternstedt, B. M., & Johansson, J. E. (2001). Is good 'quality of life' possible at the end of life? An explorative study of the experiences of a group of

- cancer patients in two different care cultures. *Journal of Clinical Nursing*, 10(4), 550-562.
- Sand, L., Strang, P., & Milberg, A. (2008). Dying cancer patients' experiences of powerlessness and helplessness. *Supportive Care in Cancer*, 16(7), 853-862.
- 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.
- Sorlie, V., Jansson, L., & Norberg, A. (2003). The meaning of being in ethically difficult care situations in pediatrics care as narrated by female registered nurses. *Scandinavian Journal of Caring Sciences*, 17(3), 285-292.
- Thomas, C., Morris, S. M., & Harman, J. C. (2002). Companions through cancer: the care given by informal carers in cancer contexts. *Social Science & Medicine*, 54(4), 529-544.
- Thulesius, H., Hakansson, A., & Petersson, K. (2003). Balancing: a basic process in end-of-life cancer care. *Qualitative Health Research*, 13(10), 1353-1377.
- Tishelman, C., Bernhardson, B. M., Blomberg, K., Borjeson, S., Franklin, L., & Ternstedt, B.M. (2004). Complexity in caring for patients with advanced cancer. *Journal of Advanced Nursing*, 45(4), 420-429.
- Wengstrom, Y., & Ekedahl, M. (2006). The art of professional development and caring in cancer nursing. *Nursing & Health Sciences*, 8(1), 20-26.
- Wenrich, M. D., Curtis, J. R., Ambrozy, D. A., Carline, J. D., Shannon, S. E., & Ramsey, P. G. (2003). Dying patients' need for emotional support and personalized care from physicians: perspectives of patients with terminal illness, families, and health care providers. *Journal of Pain and Symptom Management*, 25(3), 236-246.
- World Health Organization (2003). WHO - Definition of palliative care., Retrieved from <http://www.who.int/cancer/palliative/definition/en/>
- Widmark-Petersson, V., von Essen, L., & Sjoden, P. O. (2000). Perceptions of caring among patients with cancer and their staff. Differences and disagreements. *Cancer Nursing*, 23(1), 32-39.
- Wittink, M. N., Barg, F. K., & Gallo, J. J. (2006). Unwritten rules of talking to doctors about depression: integrating qualitative and quantitative methods. *Annals of Family Medicine*, 4(4), 302-309.