

Creating a sense of security in palliative home care: Interviews with public health nurses

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Abstract

Background: Security is a human need and the home can offer a form of security, while it can be reduced closer to end-of-life. Many patients are cared for at the end-of-life stage in their homes, and the number is expected to increase. The public health nurse works to promote good and safe palliative home care.

Aim: The study's aim is to describe how public health nurses can create a sense of security for adult patients in palliative home care.

Method: Eight public health nurses working in municipal home care were interviewed in the year 2016 in Sweden. Content analysis was used.

Results: The content analysis resulted in five main categories: patient and relatives, communication, staff, nursing planning and organisation. The results showed that the public health nurses created a relationship with patients and relatives through communication and continuity. Moreover, they were available and worked in a team towards common goals. The public health nurses' qualifications, confidence in their professional role, and experience of how care should be organised could create a sense of security for the patient and relatives.

Conclusions: The conclusion is that to understand the patient's life-world requires time and competence development in palliative care. Cooperation between municipal and county councils should be improved to create a sense of security in palliative home care.

Background

Security is a basic human need [1]. The importance of security is clarified in Swedish law. Security is an experience and can be described as three dimensions [2]. The first is the sense of security, where security is central and sought after. The second dimension is security as an inner state, basic security that has a strong connection to experiences during childhood. The third dimension is security related to the life you live, with factors outside affecting the individual, an external security.

Security has been described by adults as having inner peace and faith in themselves [3]. Security was also described as having the ability to integrate with other people as well as being safe in new routines and roles. Security can also be external security, such as having the sense of security around the clock within the walls of the home.

The Health Care Act [4] emphasises the importance of the patient's need for security. According to the Social Services Act [5], older adults are given the rights to live under safe conditions. Older adults receiving home care describe the sense of security in being at home [6]. Security may be that home care is available and that palliative care can be provided at home [7]. Person-centred care can strengthen the sense of security, taking into account the individual's life-world and values, and the ability to create a relationship [3]. Feeling seen, respected and trusted can also create a sense of security. For relatives' security, probably the most important support is that home care works well for their close relatives [7].

Care can affect the sense of security, such as the pace of determining how accessible care is experienced [7]. If security is lost, it can reduce a man's control of the situation [8]. When the patient knows that help is available when needed can increase the sense of security. It is easier for

the patient to feel secure when it is known that there is someone who has overall control over the situation [9].

Palliative care aims to relieve suffering and promote quality of life for patients with progressive, incurable illness or injury [9]. Most of those receiving palliative care wish to be cared for at home [10]. However, the desire to die at home decreases the longer the course of the disease [10]. The last stage in life is often characterised by alternating between feelings of security and insecurity [11].

Palliative care is a major part of the public health nurses' work and is often carried out at home [7]. Home care is the health care provided to patients at home, where responsibility for medical measures is coherent over time and all actions and interventions should have been preceded by care planning [12]. Home care is increasingly complex [7], and the public health nurse should have the competence to balance between proximity and distance in the relationship with the patient and relatives in the home. A professional response, which requires qualified competence, is a factor that affects the sense of security [7,13]. The staff must have a common value base, as security requires qualified care [7].

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Aim

The study's aim was to describe how the public health nurse can create a sense of security for adult patients in palliative home care.

Method

Design

A descriptive and inductive design was used [14]. The study was performed in 2016 in Sweden. Eight public health nurses were interviewed from four teams involved in municipal home care in a medium-sized town in an urban area of Sweden. Data were analysed using a qualitative content analysis method [15].

Sample and procedure

Information about the study was sent by mail to four unit managers at four municipal home care teams in a medium-sized town in Sweden. The same information letter was sent to their area manager, the head of all teams in the municipality, for approval of interviewing public health nurses. Inclusion criteria were eight public health nurses with at least three years' professional experience of caring for adult patients in the palliative home care. The unit managers gave out names of public health nurses who matched the inclusion criteria and who wanted to participate in the study. Information letters were mailed to these public health nurses, who all gave their informed consent to participate in the study.

Public health nurses worked in four teams, two in each. They were women, 35–61 years old and had 3–15 years professional experience of providing palliative care for adult patients. One public health nurse had further education in palliative care. The other seven had performed additional training in palliative care organised by the employer.

Data collection

An interview guide was created after discussions in several seminars [16]. A test interview was conducted where the questions and the layout were tested [16]. The test interview did not lead to any changes. Therefore, the test interview was included in the study.

The public health nurses chose to be interviewed at their workplace. Prior to each interview, the participant gave written informed consent to participate. The interviews were conducted in a single room at the public health nurse's workplace and took an average time of 35 minutes. Firstly, questions were asked about age, and work experience of palliative care. Then the main question was asked: Can you tell me about situations where you created a sense of security for patients in the final stages of life in the municipality's home care? The following follow-up questions were used when needed: How do/did you do...? How do/did you think...? Can you tell me more ...? Can you give examples ...? and Can you develop that? The interviews ended with the question: Is there something that you consider important that I did not ask you about?

Data analysis

A qualitative content analysis was carried out [15]. The interviews were transcribed verbatim and were first read separately by two of the authors (MB, MK) in their entirety several times in order to get an overview of the content related to the study aim. Thereafter the analysis continued with by the two authors (MB, MK) reading all interview texts, focusing on describing variations by seeing differences and similarities in the text. This was discussed at several seminars. Thereafter, meaningful units of text describing how the public health nurse can create a sense of security for adult patients in palliative

home care were identified and condensed. Finally, the analysis led to 47 codes, 14 sub-categories and five main categories (Tables 1 and 2).

Results

The results are presented through five main categories and 14 sub-categories revealed by the content analysis (Table 2)

Table 1. Example of the content analysis process

| Meaningful unit of text | Condensed unit | Code | Sub-category | Main category |
|---|---|------------|--------------|---------------|
| ...I think I can create security when the same staff are there, but it is not going to arrange all days...but I think if they recognise those who come it can create a good security... | Security is created if the same staff are coming. | Same staff | Continuity | Organisation |

Table 2. Categories and sub-categories

| Categories | Sub-categories |
|-----------------------|--------------------------------------|
| Patient and relative- | Self-determination |
| | Support for relatives |
| Communication | Create a relation |
| | Common expectations |
| | Information |
| | Dialogue |
| Staff | Documentation |
| | Competence |
| Nursing planning | Confident in their professional role |
| | Prescribed drugs |
| Organisation | Aids |
| | Continuity |
| | Availability |
| | Cooperation |

Patient and relatives

Self-determination for the patient was important to create a sense of security in palliative care. It was important that the patient controlled the dialogue with the public health nurse and that the public health nurse followed the dialogue. It was essential to respect the patient's wishes, even when the public health nurse had a different opinion. It was vital to respect whether the patient wanted to talk or not about the situation. The fact that the patient determined the care and was involved in all decisions could create a sense of security, such as deciding when to relief pain through a 'pain pump'. It was important to be aware that the public health nurse was a guest in the patient's home.

"... with her it was great. She had so much integrity, and she wanted to decide about her own health, and security for her was being able to decide for yourself ..."

Support for relatives was important in creating the sense of security for patients and relatives. The public health nurse not only cares for the patient but the entire family. Thus, it was important to set aside time and try to involve relatives in the team and to try to work towards the same goal. Sometimes patients and relatives did not want the same thing. Relatives might wish for the patient to be cared for in hospital while the patient's desire was to be cared for at home, in an environment they considered secure. Then it was important that the public health nurse listened and had a dialogue with both parties and showed that they were there, without taking the side of one or the other. It was important to inform relatives about the options that were available to support them if and when they lost their strength and needed relief.

“... to get a patient secure, it's really important with relatives who are secure. It is important that, as a public health nurse, that I can give time to relatives; otherwise they get worried and there will not be a feeling of security for the patient at home. It's all about working together, creating security together with patient and relatives...”

Communication

The public health nurses felt like guests who would work professionally yet be close to the patient to create a sense of security. It was important that there was time to create a relationship between the patient and the public health nurse, and that a contact with the hospital care was established at an early palliative stage. It was important that care was planned with the patient and relatives in order for the patient to have a sense of security. The public health nurses worked with an open mind to get to know the patient, to see the patient's needs and to perceive what mattered to the patient right now. The non-verbal communication, to “read” the patient, was easier as a relationship was created. Relatives became secure as they got to know the staff and thus brought their own security to the patient.

“... security between patient and public health nurse is best built over time [...] but there is not always time [...] but if you have time for dialogue, a nice relationship can be built ...”

“... if you meet relatives at home then you will learn about the patient in a completely different way in their home environment. It's a little special to care for patients at home, you have to take it a little as it is [...] and it's okay as long as the patient wants us to be there ...”

Common expectations were important for the sense of security by providing the patient with information about what care the public health nurse could offer. The public health nurses often worked alone in an organisation with limited resources. This could lead to shortened home visits and it could take time to get to know a patient. If the patient was initially informed when the care contact was established, it was easier for the patient to understand why home care did not always occur on the same days or at the exact time agreed. The public health nurses experienced that the patient had a sense of security if expectations of care corresponded to the care given and that they jointly conducted a dialogue about care planning. It was important that patients and staff worked towards the same goal to create a sense of security.

“... we do not have unlimited resources. I think many times they want us to be there 24 hours a day and it is not possible. If they have such a requirement maybe you have to discuss whether the patient should be at home... if that's the right option for them ...”

Security could be created when the public health nurse coordinated and there was a link between, patient, relative, physician and other collaborators. All information, oral and written, to patient and relatives was important and significant. Knowing that information was available could create a sense of security for the patient. The public health nurse was often educated the care staff about different diagnoses in order to care for the patient at home. This could create a sense of security when all staff were informed about the same thing and worked towards the same goal. For example, informing home care staff about the importance of good palliative care was important as some never or very rarely had cared for a dying person.

“... we will be a bit like the spider in a network and provide information in different directions. As I said, information is most important...”

The dialogue was one of the most important factors for creating a sense of security for the patient. It provided the patient with knowledge

that could create a sense of security for the patient. The public health nurses wanted more time for dialogue with the patient and relatives, and often felt that they had too little time to have an undisturbed dialogue.

“... the dialogue can calm and provide the security needed ...”

... the dialogue must take time. It's important to have time set aside, not to be stressed or let a phone interfere with everything for example. You should focus on the patient and really show that you want to help improve the situation...”

Nursing documentation was needed to ensure that all staff was able to safely take care of the patient. The public health nurses found that good documentation meant the patient did not have to tell everything to everyone, but instead could have a sense of security that the staff that came had knowledge about the patient's case.

“... the documentation is very important so that everyone who cares for this patient should know how to go to [...] nursing plans should be made, and all information should be easily accessible and clear ...”

Staff

It was important for patients' sense of security that the public health nurse had the competence to determine what action was important at any particular time, to make assessments and set priorities in various care situations. It was also essential that the public health nurse had knowledge of how care should be organised and to ‘be a step before’. It was important for the public health nurse to have knowledge of the different cultures of patients, for example, what to do when someone died. Home care staff did not always have knowledge about palliative care. It was therefore important to increase their competence through information meetings with the public health nurse, so that the staff had a sense of security about providing palliative care to a patient, which in turn could create a sense of security for the patient.

“... then we usually have information meetings for home care staff where you go through what to think about and how things work when caring for a dying person ...”

“... to be a step ahead as a public health nurse... I think I can provide security. Planning, organising, communicating and constantly rising before ...”

That the public health nurses were confident in their professional role was important in creating the sense of security for the patient. Experience in palliative care allowed the public health nurse to be calm and to pass on the experience to the patient. Experience provided a competence that the patient felt and trusted. Being a public health nurse who is confident in the professional role also means being honest and knowing one's limitations. This is something that can create a sense of security for the patient.

The results showed that the public health nurses' reflections with their colleagues provided a security in the professional role. The feeling of not being alone and reflecting on difficult things together makes it easier to let go of work after it has ended. This can lead to public health services working better for patients in palliative care.

“... that staff are sure when they get to the patient and show calmness... it creates security I have noticed [...] that we are calm and knowledgeable ...”

“... over the years you dare to trust yourself [...] there is no danger [...] death is not dangerous [...] you are safe in yourself and know your work task, know what to do ...”

Nursing planning

It was important to have drugs available for the patient to quickly relieve symptoms and thus avoid difficult and acute situations. The public health nurses' experience was that just the knowledge that the drugs were at home created a sense of security for the patient and family. To have drugs at home also enabled the public health nurse to relieve symptoms and help the patient quickly when severe symptoms occurred. The public health nurse rarely or ever encountered any protests from the patient when the box of prescribed drugs was placed in the home of the patient, even when it was done at an early palliative stage. Public health nurse's experience was that almost all patients wished to be cared for and die at home, and that much of the security came from the sense that there was the same drug at home as at the hospital.

"... the goal of many of our patients is to die at home and they know that we have the same drugs at home as they have in hospitals..."

Appropriate home aids can create calm and can make the care work better. Damage and unnecessary care can be avoided if appropriate aids are used in palliative care. The public health nurses' experience was that appropriate aids make the patient more independent, making daily living easier for patients receiving palliative care. The public health nurses believed that this can give the patient an increased well-being and inner security. The results showed that it is an important task for the public health nurse to ensure that the patient has appropriate aids, since this creates a sense of security.

"... independence creates dignity and inner security of the patient. Being able to do it yourself and that we can help with aids..."

Organisation

Continuity in care can create a sense of security and can lead to safer care. Patients are more open and feel more secure with staff they know. A sense of security can be created when the patient knows when the public health nurse is coming and also know that they can come if needed. With more staff, the more the sense of security was decreased, since the patients appreciated well-known staff. The patients felt more secure during daytime than at night, when the care was often provided by unknown staff.

"... we create security for a very sick person, by showing that we are there [...] dare to be there [...] and we build it by appointing someone to be responsible for that patient and meeting up from the start..."

"... they were very worried there at home but once they understood that I could come every day until they felt calm and secure, the worries immediately ended..."

The availability of home care provided the patient with a sense of security. The availability was sometimes crucial if the patient chose to be cared for at home. A sense of security could be created when home nursing was available for the patient and relatives at all hours, every day, all year round. It was not always that all phone calls led to home visits, since a short phone call could create a sense of security. The patient or his family could have home visits, so it was important for security, knowing that they could receive it regardless of the time and day. Availability can also create a sense of security for relatives, which in turn could create a sense of security for the patient.

"... and after many frequent visits, it had calmed down a bit so that they were safe at home. They [patient and relatives] knew that they could call us around the clock and that we would respond even on Christmas

Eve [...] We planned a check-in every other day, which they thought was enough. We were just a dialogue away and they were quite calm about it ... "

The cooperation with social care staff and other care providers was important to create a sense of security for the patient. It was also important that social care staff received the information they needed from the public health nurse to give the patient good palliative care. The public health nurse acted as the patient's elected representative and was responsible for contact with other actors, something that the patient and relatives often appreciated and that gave them a sense of security. The cooperation with the county council's palliative unit could contribute to the patient's sense of security, for example, the public health nurse together with the physician making home visits as often as required. Then the patient could be informed directly by the physician about the care planning.

"... patients feel secure if we coordinate the care together with the hospital, if we cooperate and can arrange physician visits at home ..."

"... a safe and informative physician creates a secure patient together with us ... that's just as it is ..."

In summary, the results showed that the public health nurse could create a sense of security for the patient and relatives through communication, nursing planning, competence, being confident in their professional role, and organisation. Patient and relatives are parts of the team, together with the public health nurse and staff. They work together to create a sense of security for the patient in palliative home care.

Ethical considerations

Conventional research ethical principles in humanitarian and social science research as formulated in ethical research guidelines and in Swedish ethics testing legislation have been followed, taking into account information, consent, confidentiality and usage requirements [17]. In accordance with Swedish legislation, the questions in this study do not concern sensitive personal data.

Methodological considerations

In order to achieve trustworthiness, the analysis was discussed within the research group and in several seminars in order to achieve consistency [14]. The intention was to describe the method and results with quotes as clearly as possible. The Swedish context and the sample size mean the results have limited transferability, but other public health nurses in similar contexts can recognise themselves in the results. There were no ethical problems.

Discussion

The results showed that it was important that the public health nurse respected that they were a guest in the patient's home, where the patient decides. This is in line with previous research, which found that the public health nurse should have an understanding of what the home symbolises for the patient [7]. In order to practice nursing at home, the public health nurse was required to accept the patient's lifestyle, culture and the way they have it at home. The public health nurse described the importance for creating a sense of security of the patient being able to decide where to be cared for at the end-of-life stage. It is consistent with research that the patient's autonomy should be respected at home, since there may be time to sit down in the patient's safe environment and thus increase the understanding of the patient [18].

Care in the patient's home should be based on a caring science theory that the patient is at the centre of care and is an expert on herself [8]. The daily life of the patient is important when care is given at home and must be taken seriously by the staff. Our reflection is that care becomes more personal when it occurs at home and more on the patient's terms, such that the public health nurse has to have increased consideration for patient self-determination and must support the patient's decision if the patient wants to be cared for in a hospital. Our experience is that relatives often experience the situation at home as insecure, which causes some patients to be cared for in hospital. It is important to be aware of this.

The public health nurses considered that medical aids increased the patient's freedom, as the patient could determine when to take pain relief. As a result, the patient became more independent of the public health nurse which could create a sense of security. Earlier research [19] confirmed that medical aids could give the patient freedom in the palliative care. It requires the public health nurse to receive continuous training in the handling of the aids the patient is using. Our experience is that patients in palliative care often have medical aids and that the public health nurse often works alone in the patient's home. This means that the public health nurse must know how the aids work. We believe that it is difficult to create a sense of security for the patient unless the staff can handle the technological aids.

The results showed that to create a sense of security, it is important to create a relationship with the patient by learning and acquiring knowledge about the patient's individual needs and wishes. Earlier research [20] emphasised the importance of a good relationship between the patient and the public health nurse in palliative care. The relationship can lead to patients feeling more secure in palliative care.

The public health nurses in this study described the benefit of getting to know the patient at an early stage in order to create a relationship. This was confirmed by research [21], which found that it is crucial to come in at an early stage to establish a good relationship. Establishing a relationship with the patient and relatives early creates the conditions for person-centred care in palliative care. Our reflection is that it takes time to create a relationship that allows the patient to feel secure and to trust the public health nurse. If home care is provided at an early palliative phase, the public health nurse may focus on getting to know the patient during a calmer period before the patient becomes too ill to form a relationship.

The results showed that the public health nurse considered it important that the patient had knowledge about the help they could receive. How the public health nurse worked was considered important, and the patient should feel that they were working together towards the same goal. It was also considered important that the patient's and the public health nurse's expectations for care were consistent [22]. Information is crucial as it is the basis for the patient's decision. The information should be realistic, as it may be difficult for the public health nurse to meet the patient's and relatives' expectations of care. Our reflection is that information for patients about home care should be given at an early stage. The information should also be provided by staff who are well aware of the municipality's home care system, to create conditions for properly functioning care and to create a sense of security.

Communication and information between the public health nurse, patient and relatives but also with other care staff were considered prerequisites for safe care. It was considered important that everyone involved knew what was going on. This has been confirmed by research,

which states that communication is the key in good palliative care [23]. Care will be safer and better for the patient if all care professionals have knowledge of how to care for the patient. Our reflection is that easy-to-understand information and good communication can provide a secure care situation for the patient in palliative care and that this information is documented. As the work situation for the public health nurse is today; often working alone, unscheduled visits with emergency measures, it is not always possible to get prepared because information is not available outside the public health nurse's office.

The public health nurses considered that the sense of security increased if the patient had the right aids to facilitate everyday life. This was consistent with research [24], which also emphasised the importance of the public health nurse assessing the need for help in the home. Our reflection is that the public health nurse in palliative care home care is professional in planning care and can assess the need for aid. Another reflection is that sometimes there may be little time to prepare to take a patient home from the hospital. Better communication between municipality and county council is desirable and would be a benefit to patient security.

The results showed the importance of competence among staff in palliative care. The public health nurse assesses, prioritises and organises care in a way that can create a sense of security for the patient. In the competence descriptions for public health nurses, competence is described as the ability and willingness to perform an action by using knowledge and skills [25]. The public health nurses' responsibilities in home care are broad. Their main tasks are to assess, decide, and formulate goals according to the needs of the patient [7]. To handle the tasks and meet the patient's needs, the public health nurse is required to demonstrate competence development.

Our reflection is that it can be difficult to maintain competence within the public health nurse's broad field of responsibility. Continuous competence development is important in order to meet the needs of patients in palliative home care. We believe that the public health nurses in the home care do not receive competence development in palliative care, arranged by the employer, to the extent they wish. We agree with previous research that questions whether public health professionals' professional knowledge is too experience-based and is not scientifically anchored [25]. The public health nurse is better able to care for the patient if the care rests on a caring science basis [8].

The public health nurse's collaboration with colleagues and other actors in care can create a sense of security for patients in palliative home care. This is consistent with research [26] which reported that teamwork with the patient in the palliative care can create a sense of security for the patient and relatives. Our reflection is that teamwork with different professions is necessary as the care of the patient can be highlighted from several perspectives, which contributes to a holistic view. When the public health nurse has a holistic view, it provides a good opportunity to create a sense of security for the patient. Our reflection is that an overall vision can increase understanding of the patient's individual needs and wishes, and thereby create a sense of security.

The public health nurses considered that they served as a confidence elected for the patient by managing the care contact with other actors, thus relieving the patient and relatives in a difficult situation. This is in line with what previous research [18] has reported, i.e. that the public health nurse acted as the patient's attorney by coordinating care for the patient. Our reflection is that the patient and relatives should be given the opportunity to relax and care for each other during this final

stage and should be able to hand over coordination of care to the public health services.

The results showed that it was important that the public health nurse was responsible for the patient's care. To create a feeling of security for the patient, it was good that as few staff as possible were involved in nursing, as it could be difficult to get to know new staff in the end-of-life period. The public health nurse believed that the patient could feel a sense of security when they knew who was doing the home visit. This is also described in previous research [18] which found that the patient should benefit from continuity in the municipality's home care, which means that staff are few and preferably the same staff make home visits. The public health nurses said that continuity of staff could create a sense of security for the patient in home care. Our experience of meeting patients in palliative home care is that it is important to minimise the number of new staff attending the patient. The patient and relatives want to deal with staff they know as this can create a sense of security for them in an exposed and vulnerable situation.

Conclusions and clinical implications

Public health nurses can create a sense of security in adult patients' palliative home care. However, doing so may be a challenge as the cooperation between the municipality and county council should be improved. Security can be promoted when the public health nurse has accurate information, which was sometimes described as difficult as access to journals was missing when working outside their office. It is important to listen to the patient and relatives, and to create a relationship and plan nursing based on the needs of the patient and their resources in palliative home care.

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