Addressing sexual issues in palliative care : a qualitative study on nurses' attitudes, roles and experiences

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Addressing sexual issues in palliative care: A qualitative study on nurses' attitudes, roles and experiences

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Abstract

Aim: To explore palliative care nurses' attitudes, roles and concrete experience with regard to addressing sexual issues in their daily practice.

Background: Patients and their partners in palliative care might experience dramatic changes in their sexuality and want nurses to provide the opportunity to address them. Moreover, it is argued that the holistic philosophy of palliative care encourages nurses working in this area to include sexual issues in their daily care. It is, however, unknown how palliative care nurses address sexual issues

Design: A generic qualitative study was performed.

Methods: In total, 21 in-depth interviews were done with nurses from different facilities of palliative care networks in Flanders. Data were collected between September 2014 and September 2016 and thematic analysis was used to analyse the data.

Results: It was found that the way palliative care nurses addressed sexual issues was clearly influenced by their own interpretation of the philosophical principles underlying palliative care. The different interpretations of these basic principles create tensions for nurses about how to address sexual issues in the daily practice of palliative care and nurses vary in their reactions to these tensions. The present findings show that palliative care nurses – when they

were able to overcome these tensions – use a "sex-positive approach" that fits with their tendency to focus on quality of life.

Conclusion: Out of the results of this study, we made a list of good practices for palliative care nurses addressing sexual issues. This list can be used in nursing educational programs.

Keywords: Qualitative research, thematic analysis, terminal illness, palliative care, sexuality, couple, nursing, communication

SUMMARY STATEMENT

Why is this research needed?

- Patients in palliative care and their partners expect their nurses to instigate the discussion about sexual issues in the palliative phase.
- The holistic philosophy in palliative care encourages nurses to include sexual issues in their daily care as well.
- In general, discussing sexual issues with patients/partners is challenging for nurses, but it is unknown how nurses working in palliative care address sexual issues.

What are the key findings?

- The way palliative care nurses address sexual issues is clearly influenced by their own interpretation of the philosophical principles underlying palliative care.
- Different interpretations of the philosophy of palliative care create tensions about how to address sexual issues and nurses vary in their reactions to these tensions.

- Palliative care nurses can use a "sex-positive approach", aligning with their tendency to focus on quality of life.

How should the findings be used to influence policy/practice/research/education?

- The results show the usefulness of several interpersonal communication strategies, which might be added to the general models used in nursing care for addressing sexual issues.
- Recommendations on addressing sexuality in palliative care and how to use these in nursing educational programs are formulated.

INTRODUCTION

When entering the palliative stage of life, experiences in the realm of sexuality and their significance may change profoundly for patients and their partners (Ananth, Jones, King, & Tookman, 2003; Lemieux, Kaiser, Pereira, & Meadows, 2004; Leung, Goldfarb, & Dizon, 2016; Taylor, 2014; Vitrano, Catania, & Mercadante, 2011). For instance, the intense emotional reactions provoked by the experience of proximity to death may have an influence on the sexual experience of both patients and partners: some couples have sexual interactions to reinforce their emotional connectedness or to console each other, while others restrain from sexuality due to altered feelings or miscommunication (Taylor, 2014). Moreover, physical factors related to the palliative stage (e.g., immobility and general malaise) may decrease sexual desire and hinder the spontaneous expression of sexuality (4). Furthermore, social or environmental conditions (e.g. a single hospital bed or a lack of privacy in inpatient settings may also be barriers to the expression of sexuality(Lemieux et al., 2004; Shell, 2008).

Background

Although sexual issues are often surrounded by taboos in health care, patients and/or partners expect palliative healthcare providers to instigate the discussion about sexual issues related to their illness (Ananth et al., 2003; Flynn et al., 2012; Hordern & Street, 2007b; Leung et al., 2016; Stead, Brown, Fallowfield, & Selby, 2003). This is also in line with recommendations formulated in the National Consensus for Quality Palliative Care in the United States, where sexuality is recognized as an important component that needs to be addressed in palliative care (National Consensus Project for Quality Palliative Care, 2012). Moreover, the World Health Organisation (WHO, 2010) positions nurses at the forefront of the delivery of "sexual health care".

However, research has shown that discussing sexual issues with patients/partners is still challenging and difficult for nurses (Hordern & Street, 2007; Lindau, Surawska, Paice, & Baron, 2011; Perz, Ussher, & Gilbert, 2014; Stead et al., 2003, Dyer & das Nair, 2013). Nurses feel responsible for doing so, but the topic often provokes conflicting feelings such as fear and embarrassment (Saunamäki & Engström, 2014). They also frequently mention a lack of knowledge and skills to adequately initiate a discussion about sexual issues (Higgins, Barker, & Begley, 2006). As a consequence, they often deny, ignore, or avoid dealing with sexual issues in their work (Hordern & Street, 2007b). In general, they feel more comfortable addressing the 'medical(ised)' aspects of sexuality (e.g. erectile dysfunction, vaginal dryness), than the emotional and relational aspects, as often preferred by the patients/partners involved (Hordern & Street, 2007).

It has been argued that the holistic philosophy and patient-centred approach in palliative care (Pastrana, Junger, Ostgathe, Elsner, & Radbruch, 2008) encourages nurses to include sexual issues in their daily care as well (Bowden & Bliss, 2009; Lemieux et al., 2004; Leung et al., 2016; Taylor, 2014). On the other hand, there are also reasons to doubt – in practice – that sexuality is likely to be addressed in palliative care, especially in advanced stages of disease: recent research shows that barriers to addressing sexual concerns may *increase* as the disease progresses (Reese et al., 2017). No empirical research so far has specifically investigated how nurses working in palliative care do address these sexual issues.

Therefore, the central research question of the current study was: : "What are palliative care nurses' experiences with sexuality in their daily practice?" and more specifically "What are their attitudes about sexuality in palliative care, their assumed roles towards addressing sexuality and their specific experiences with addressing sexual issues in palliative care?"

THE STUDY

Aim

The aim of this research is to explore palliative care nurses' attitudes, roles and concrete experience with regard to addressing sexual issues in their daily practice.

Design

We performed a "generic qualitative study", as our research questions did not fit neatly within a single established methodology (Kahlke, 2014). More specifically we chose "interpretive description", a subgenre of generic study developed to address the need in

nursing research for a pragmatic, contextualized qualitative approach that draws on experience from clinical practice, is translated easily into the practice setting and reflects nursing's unique mandate and epistemological foundations (Thorne, Kirkham, & MacDonald, 1997). The generic qualitative study is based on in-depth interviews, as we wanted to provide detailed information about the palliative care nurses thoughts, experiences and behaviour and as in-depth interviews may provide a relaxed atmosphere to collect information - which might be necessary for sensitive subjects such as sexuality (Boyce & Neale, 2006). To analyse the data, we used thematic analysis (Braun & Clarke, 2006) .

Participants

Our study was conducted in Flanders, the Dutch speaking half of Belgium. Flanders has well-developed and varied palliative care services, formally coordinated by regional palliative care networks, consisting of residential palliative care units and palliative support teams in hospitals, palliative home care teams visiting patients at home or in nursing homes and palliative day care facilities offering ambulatory support during the day (see figure 1).

For this study, we recruited nurses working in these different facilities. Recruitment was done through the directors of these facilities. In total, 21 nurses were interviewed, based on willingness and availability at the time: two from palliative support teams in hospitals, six from residential palliative care units, 11 from palliative home care teams and two from palliative day care facilities. All interviews were done in a private room at their workplaces. Table 1 gives an overview of the participating nurses' characteristics.

Data collection

In-depth interviews were conducted with the palliative care nurses. At the start of the interview, we told the participants we were interested in how they addressed their patients and partners' sexual issues in everyday work. To open the topic, we shared with them Gilley's broad conceptualisation of sexuality in the context of palliative care, stating that sexuality includes both expression of emotional needs through physical intimacy and a more erotic interpretation (Gilley, 2000). We asked nurses about their experiences with addressing sexual issues, what they find difficult about it, what they find easy, etc. The interview guide was used flexibly and the interviewer used prompting and probing techniques (see addendum for interview guide).

All interviews took place between September 2014 and September 2016 and were done by a female sexologist (CB, first author of this article), who had no personal connection with the nurses. Interviews took between one and two hours, were audio-taped and transcribed *verbatim*. Data collection ended when saturation was reached; i.e., when additional data did not reveal new ideas.

Ethical considerations

This study was approved by the Ethical Committee of the Academic Hospital of a University (B.U.N. 143201420594) and data collection and analyses were carried out with care and concern while maintaining total privacy and confidentiality for the participants. To reach this goal all personal information was deleted before transcription and representation of the data, so that neither nurses, nor their working area could be traced.

Data analysis

We performed our analysis according to the six phases of thematic analysis offered by Braun and Clarke (2006). We identified themes at a latent level, which means that we interpreted the nurses' accounts, examining underlying ideas, assumptions and conceptualisations/ideologies. In our case, we interpreted the nurses' accounts in relationship with the philosophical principles of palliative care (Benahun, 2003; Giley, 2000). A detailed description of the different phases of analysis can be found in Table 2. The final thematic map is shown in figure 2.

The first author (CB) did the analysis under supervision of a research team, which met regularly during the whole trajectory of the research process. During these meetings, the first author presented her rationale for data collection, analysis and her interpretation of the data, to enhance reflexivity and to check plausibility and coherence in her interpretation. The members of the research team looked at the data from a different research and health work perspectives: i.e., JB as a public health scientist and nurse, PE as a sex researcher and sex- and marital therapist and LP as a health scientist and general practitioner. We used NVIVO 10 to guide our thematic analysis.

Rigour

To ensure rigour in our qualitative study, we ensured that that the typical and atypical elements of the data were depicted in the descriptions, thereby providing a plurality of reactions to the subject. As well, we ensured that our data analysis was done by additional researchers (Sandelowski, 1986; Guba & Lincoln, 1981). Also, we reported our study in a comprehensive and transparent way by the aid of the COREQ checklist (Tong, Sainsbury, &

Craig, 2007), a checklist that aims to promite complete and transparent reporting amongst researchers (see addendum).

FINDINGS

We found that the way palliative care nurses addressed sexual issues was clearly influenced by their own interpretation of the philosophical principles underlying palliative care. These principles relate to the focus of care, content of care and the nurse-patient relationship (see fig 2). Our findings suggest that different interpretations of these basic principles create tensions between nurses about how to address sexual issues in the daily practice of palliative care and that nurses vary in their reactions and responses to these tensions. In the subsequent sections, we discuss these philosophical principles and their interpretations, as well the consequences for the way nurses address sexual issues.

Focus of care on living or dying: Unravelling or containing sexual issues?

A first philosophical principle underlying palliative care is that the focus of the nurses' care is to promote the 'quality of life' (QOL) of patients. When put into practice, this focus on quality of 'life', however, does not imply that nurses need to ignore the fact that the patient is dying. The search of a balance between living and dying creates tensions about how to address sexual issues, in two ways: the tension to see sexuality as a part of QOL or as a way of denying imminent death and the tension between "unravelling" or "containing" sexual issues.

Firstly, there is the *tension between interpreting sexuality either as 'a symbol/ part of QOL' or as 'a symbol of ignoring the reality of dying'.* Nurses who saw sexuality as a part of QOL mentioned several advantages of sexuality for QOL: e.g. *"it diminishes terminal agitation"* or *"it's an effective way of communicating when verbal communication is getting more difficult."* This tendency to see sexuality as part of QOL was found more frequently where they rephrased it as "physical intimacy":

> Nurse, m, residential palliative unit, 48y: "terminal agitation will occur less when two people can feel each other's presence in the same bed… even if it just means lying under the same cover in the same bed, holding each other …"

These nurses often tried to live up to this point of view in their every day care by consciously providing opportunities for patients and partners to be sexually intimate: e.g., they tried to involve the partner in giving physical comfort to the patient; they adapted (hospital) infrastructure to create a facilitating environment for physical intimacy, e.g., by putting a second bed in the room or encouraging the couple to lie in bed together; ensuring privacy by knocking on the door before entering.

Other nurses, however, interpreted a couple's need/request to resolve sexual issues – especially when understood in a limited erotic sense, i.e., penetrative intercourse – as a symbol of the incapability of a patient/partner to "accept" the fact that they are dying; they regarded this need as incompatible with "a good death":

> Nurse, f, residential palliative unit, 58y: "He did say that he needed sex, but couldn't catch his breath in his wheelchair, let alone if he was supposed to be having sex in some way. That man was so determined, he didn't want to adapt at all. I know it sent shockwaves through the team here."

When confronted with questions about sexual issues, they tended (sometimes prematurely) to work towards acceptance of the sexual loss, instead of exploring feelings or expectations about these sexual issues:

> Nurse, f, home care organisation, 48y: "A woman said to me recently, although she was severely ill, that she missed sexual intimacy with her husband who no longer dared to have sex with her. Now that I think about it, I was too hasty with her, I had an immediate answer ready: "do you still cuddle? Yes? Well that's nice too, isn't it…"

Secondly, there is the tension between containing sexual issues and unravelling them as part of the "personal growth" inherent to QOL. Personal growth refers to the idea that unresolved issues – of which sexual issues may be one – can be (re)solved and offer partners/patients an opportunity for further growth.

According to this philosophical principle, nurses can help patients/partners to resolve sexual issues that are at stake at the end of life. However, when put into practice, there is the risk that unresolved sexual issues may impose a significant threat to a couples' relationship or personal wellbeing. Nurses said they have to be attentive not to unpack problems when there

is not enough time left to work them through – due to the imminent death of the patient – as by doing so they may risk preventing "a good death". Thus, the fact that the patient is dying demands a balanced approach of psychosocial care and this is especially so when it comes to addressing sexual issues:

> Nurse, f, palliative day care center, 40y: "The possibilities are often very limited. We don't have the opportunity to intervene… usually all we can do is limit the damage. By looking after them as well as possible. That is palliative care."

When nurses focused more on dying and thus on the limited time available, they reported being hesitant to unravel sexual issues. They tended to categorize sexual issues as structural problems deeply rooted in the history of a relationship or a person, that need more time and effort to resolve than the limited time they can work with the patient/partner. They mentioned feelings of "helplessness" and tended to listen to stories about sexual issues rather passively, reassuring themselves that giving patients/partners the opportunity to express their concerns was the only matter that fell within the scope of their task:

> Nurse, f, home care organisation, 48y: "Yes. I let her tell her story (about her sexual issues) and acknowledged her but that was all, really. Afterwards she didn't come back to me with it and I didn't raise the subject again either."

When nurses focused more on the possibility of personal growth, they tended to be more open to actively exploring sexual issues with the couple. They did not shy away from sexual issues, but assumed that by exploring the issue together, for example by probing to help

patients/partners to better understand what is going on with their sexuality, the acquired insights could help patients/partners to unravel sexual issues:

> Nurse, f, home care organisation, 57y: "If they say something like, my husband doesn't even touch me, I say: was it different before? Then they can realise themselves that… my husband was never really the touchy-feely type or much of a cuddling kind of person, if I have never said anything about it, it's going to be difficult to change him now. Or they might say, yes, actually I kept him at a distance, so he started to distance himself… maybe there is something I can do to change that… that's how people become aware of it themselves.

Content of palliative care: "Holistic sexuality-inclusive" or "holistic sexuality-exclusive"

A second philosophical principle underlying palliative care is that the content of the nurses' care is "holistic", i.e. that it comprises somatic, psychological, social/cultural and spiritual aspects. As sexuality is a multi-dimensional phenomenon, it is related to all these aspects. However, nurses' accounts revealed that the palliative phase is mainly associated with bodily deterioration and physical suffering, which creates tension about the question whether sexual issues are "a priority" or not.

When nurses said that they were giving sexual issues as much priority as other care needs, they negotiated with patients/partners about possible implications of certain medical or infrastructural interventions for their sexuality, e.g. as they found that sometimes patients/partners chose the intimacy of sleeping together over the possible discomfort this entails:

> Nurse, f, home care organisation, 38y: "In the beginning of my career, I thought I had to decide when to set up a hospital bed. Now, as a palliative care nurse, I find there is no point insisting because they already have to give up so much as a couple. So I leave it up to them. As long as the partner is prepared to get her husband into bed every evening, who am I to say it's wrong and that they need a hospital bed. It's important to them."

Another example is how symptom management is sometimes adapted to enable sexual expression:

> Nurse, f, home care organisation, 28y: "I take into account the sexual implications if I am putting pain pumps in, because they make you drowsy, so I ask when the partner is home and if that is the time they want to spend together. And then I sort out the pain pump at a time that suits them, so they can have their intimacy."

Being confronted with the tensions in holistic care described above, other nurses sometimes stated to rely on and work with a hierarchy of care where symptom management was prioritized above sexual issues and management of them, reflecting their doubts about sexual issues being a priority, or stating that symptom management needs to come first, especially when time is limited:

> Nurse, f, home care organisation, 51y: "When there is pain for example or another symptom, that symptom is at the foreground. Then intimacy and sexuality are right down at the bottom of the pile. If someone is in constant pain, we try to do something

about that. And then things like sexuality might come up afterwards. But as long as there is a complaint or symptom, there is no room for things like that."

Nurse-patient relationship: From "giving advice" to "exploring the issue" together.

A third philosophical principle of palliative care emphasizes the empowerment of the patient/partner in the nurse-patient relationship. This means that patients/partners are seen as (co-)decision-makers and that – instead of organizing care based on fixed procedures – nurses' care is primarily led by the needs of patients/partners and at their pace. It moves away from only the professional having control, to give the patient/partner as much sense of autonomy as possible:

Nurse, m, residential palliative unit, 48y: "Actually, we listen to the patient and their family, what they bring up, what they need. And if they talk about things like touch, intimacy, sexuality, we pick up on them. Then we ask more questions and we might be able to work with it… but we don't have any standard questions in palliative care."

However, nurses also knew that patients/partners may be hesitant to broach sensitive subjects such as sexual issues. This leaves them with a tension to choose between proactively initiating an exploratory conversation about sexual issues or waiting for patients/partners to initiate the topic themselves.

Some nurses chose not to proactively initiate conversations about sexuality because they felt insecure or unqualified to do so or believed they lacked "expertise" in the field of sexuality. They assumed that addressing sexuality issues in palliative care meant that they had to give "advice" about sexual issues and suggest "solutions" to the concrete problems the patients'/partners put forward. They shifted responsibility for broaching sexual issues towards psychologists or GPs.

Furthermore, they mentioned not seeing patients/partners frequently enough to initiate conversations about sexual issues, being convinced that sensitive conversations – whether by patients/partners or nurses – are only possible in a close professional relationship.

Other nurses however acknowledged not having enough experience to give clear-cut specialised advice about specific sexual issues and also didn't find it necessary to do so. They assumed that addressing sexuality issues in palliative care meant that they "talk about", "explore" and "acknowledge" the emotions linked to sexual issues, together with the patient/partner:

> Nurse, f, home care organisation, 28y: "Then I ask: how have you always approached sex… To give them a bit of insight and so that they do… yes… feel like, do I still want to do that, how am I going to do it and then we also always ask, can you do that yourself or do you need help… we can help… Do you have questions for us or is there something we can do about it? So, actually it's the same for all issues, sexuality too, we have to approach things in the same way actually."

These nurses also reported using facilitating techniques initiating discussion, such as taking sexual issues seriously, even if the patient/partner is laughing, or putting their observations into words:

> Nurse, f, residential palliative unit, 41y: "Talking about sexuality does come up too when we are washing patients, for example. They might say about their intimate body parts, "there used to be more life in it". If you brush it off and laugh, an important moment is lost. But if you detect these things carefully and delve deeper and ask if they need it, those conversations start."

They mentioned that an open, responsive attitude on the part of the nurse and the intensity of the encounter is more critical than the closeness of the relationship or the frequency of encounters.

These nurses said they are also not free from uncomfortable feelings that may prevent them from identifying opportunities for addressing sexual issues, but when this happens, they often take a reflective position and discuss their hesitance with colleagues or in team meetings.

DISCUSSION

This study provides empirical data for the idea that addressing sexual issues falls within the remit of holistic palliative care, but also reveals that nurses experience difficulties and tensions when confronted with patients and partners' sexual issues in their daily practice.

More specifically, nurses reported being confronted with certain tensions that can be related to the basic principles of holistic palliative care. We found a tension about whether care should focus mainly on living than on dying, which resulted in tension for nurses about what to do, i.e. "unravel" or "contain" sexual issues. Furthermore, we found tension about the importance of sexual issues at the end of life and how they related to other care needs (priority or not). Finally, we found tension about how "the empowerment of the patient/partner" was concretely translated within the nurse-patient relationship by taking more of an initiating or waiting attitude towards conversations about sexual issues. This study demonstrates how the underlying discourse from a specific nursing area might interact with the nurses' concrete attitudes and behaviour, thereby offering a broader perspective on the results of other studies on this subject, studies that mainly focus on personal factors such as assumptions, values and comfort or discomfort in individual nurses (Gleeson & Hazell, 2017; Magnan & Reynolds, 2006; Reese et al., 2017)

However, besides the philosophical principles of palliative care, several other important factors that may influence the nurses' way of dealing with these tensions emerged from our study: the type/kind of sexual issue, the organizational structure/context of the care and the possible "techniques" available to address the specific issue. Nurses seem less prone to translate palliative care principles into practice when it concerns more erotically explicit issues of sexuality than when the issues lean towards physical intimacy. This might be also due to stereotypes about the asexuality of old(er) and ill persons (Taylor, & Gosney, 2011). Nurses were also less prone to address sexuality according to the principles of palliative care when they perceive a lack of time and space to give appropriate care. Moreover, they tend to handle tensions more easily when the way of addressing sexual issues is close to their daily

tasks as a palliative care nurse, e.g., letting the partner help with comfort care, or using communication skills such as empathic listening.

Although our sample contained a differentiation on gender, age and palliative care services, our analysis did not reveal differences on these factors. The research literature is also inconclusive/controversial whether nurses-related issues might influence nurses' attitudes towards sexuality (Kotronoulas, Papadopoulou, & Patiraki, 2009). Probably, it might be that the philosophic principles of palliative care might weight heavier on the attitude and experience of addressing sexuality than the type of palliative care service. More research might be needed to explore these differences in-depth.

Our results also show that palliative care nurses – when they were able to overcome the above described tensions – use a "sex-positive approach". A sex-positive approach refers to a recent discourse emphasizing the pleasurable aspects of sexuality: it means being open, communicative and accepting of individual differences regarding sexuality and diversity in sexual behaviour (Williams, Thomas, Prior, & Walters, 2015). It is clear that the philosophy of palliative care – with its focus on quality of life, on being holistic and by emphasizing the empowerment of the patient and partner in the nurse-patient relationship – aligns with this sex-positive approach.

In our results, this sex-positive approach is put into practice by nurses by "encouraging the couple to be 'sexually' intimate, by creating a positive-sex environment, by being open to actively exploring issues". These results reflect how the tendency in the general (nursing) literature about serious illness and sexuality evolves from a predominantly "sex-negative"

framework for conducting research about sexuality or informing practice (Hordern, 2008) to a more patient-centred, positive approach (Reisman & Gianotten, 2017). The current finding show that this positive approach can also be found in the attitudes and daily practice of palliative care nurses on the condition that nurses able to overcome the tensions between philosophy and practice.

What is more, the empowering discourse in palliative care teaches us that addressing sexuality is a "negotiated process" rather than a "unilateral way" of giving information (the nurse) and receiving information (the patient). Most literature emphasizes that informing patients and partners is the primary way to address sexual issues and the general educational models for addressing sexual issues usually applied in the field of oncology/nursing care in general emphasize this "one-way" information-giving as well (Ayaz & Kubilay, 2009; Taylor & Davis, 2006; Reese et al. , 2017). The results of this study show the usefulness of more interpersonal communication strategies (e.g., exploring feelings, active listening, probing, negotiating), which might be added to the general models used in nursing care as effective ways of addressing sexual issues.

Limitations

The transferability of the data is limited. We partly recruited nurses based on their motivation to be interviewed for this study. This possibly leads to some bias, because of their explicit willingness to talk about sexuality. Our study further focuses exclusively on palliative care nurses working in the palliative care services as organized in Flanders, Belgium, excluding nurses caring for terminally ill patients in other work settings (e.g., nurses working on oncology wards). Moreover, the settings where palliative care is provided (i.e. ambulant and

residential care) are diverse and this might also have implications for the way palliative care nurses act, which we did not investigate in depth in this study. It might be interesting to do further research into the different groups of nurses working with terminally ill patients, as well researching how the different settings where the care is delivered shape communication by health professionals in palliative care and practices surrounding sexual issues. However, the narratives of the palliative care nurses might transcend their immediate context and be transferable in other (West-) European states with a similar developed health care system.

More or less absent from the accounts of the nurses was there experience with and attitude towards different sexualities in palliative care. This might be because we did not explicitly asked questions about this topic, but the invisibility of this subjects in the accounts might suggest a heteronormative attitude that denies diversity in sexual identities (Simpson, Almack & Walthery, 2016) Thus it might also be worth exploring nurses' attitudes to or experience with different sexualities in palliative care as well. Also, we did not have in-depth data for other possible influences on the way nurses addressed sexual issues, such as the personal context of the nurse, the gender of the nurse vs. the gender of the patient/partner, the personality of the patient/partner, the nurses' experiences with their own sexuality, etc. All these could be further areas of investigation.

CONCLUSIONS

Palliative care nurses' attitudes, roles and concrete experience with regard to addressing sexual issues was clearly influenced by their own interpretation of the philosophical principles underlying palliative care. The different interpretations of these basic principles create tensions for nurses about how to address sexual issues in the daily practice of palliative

care and nurses vary in their reactions to these tensions. Our results show that palliative care nurses – when they were able to overcome these tensions –use a "sex-positive approach" that fits with their tendency to focus on quality of life.

The findings of this study are useful for clinical practice, as the focus of our study goes beyond listing barriers to addressing of sexual issues – as often found in nursing literature (Dyer & das Nair, 2013) – towards showing *how* nurses deal with sexual issues. More specifically, we made recommendations on addressing sexuality in palliative care, which can be used in nursing educational programs in list form (table 3), which we retrieved from our data. We call them "good practices" as these are the attitudes and skills of nurses when they were able to translate the philosophical principles of palliative care into practice. These recommendations can be used in educational programs in palliative care, as well these can form the basis of evaluation and amendment in the light of experience. Further research might investigate whether the good practices of palliative care nurses are applicable in other contexts as well, for example in oncology healthcare.

Educational programs in palliative care can further use the findings of this paper to help nurses becoming more aware of how basic care principles (e.g. the philosophy of palliative care) influence their way of addressing sexual issues, which may enhance their reflexivity.

Author Contributions:

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

2) drafting the article or revising it critically for important intellectual content.

* http://www.icmje.org/recommendations/

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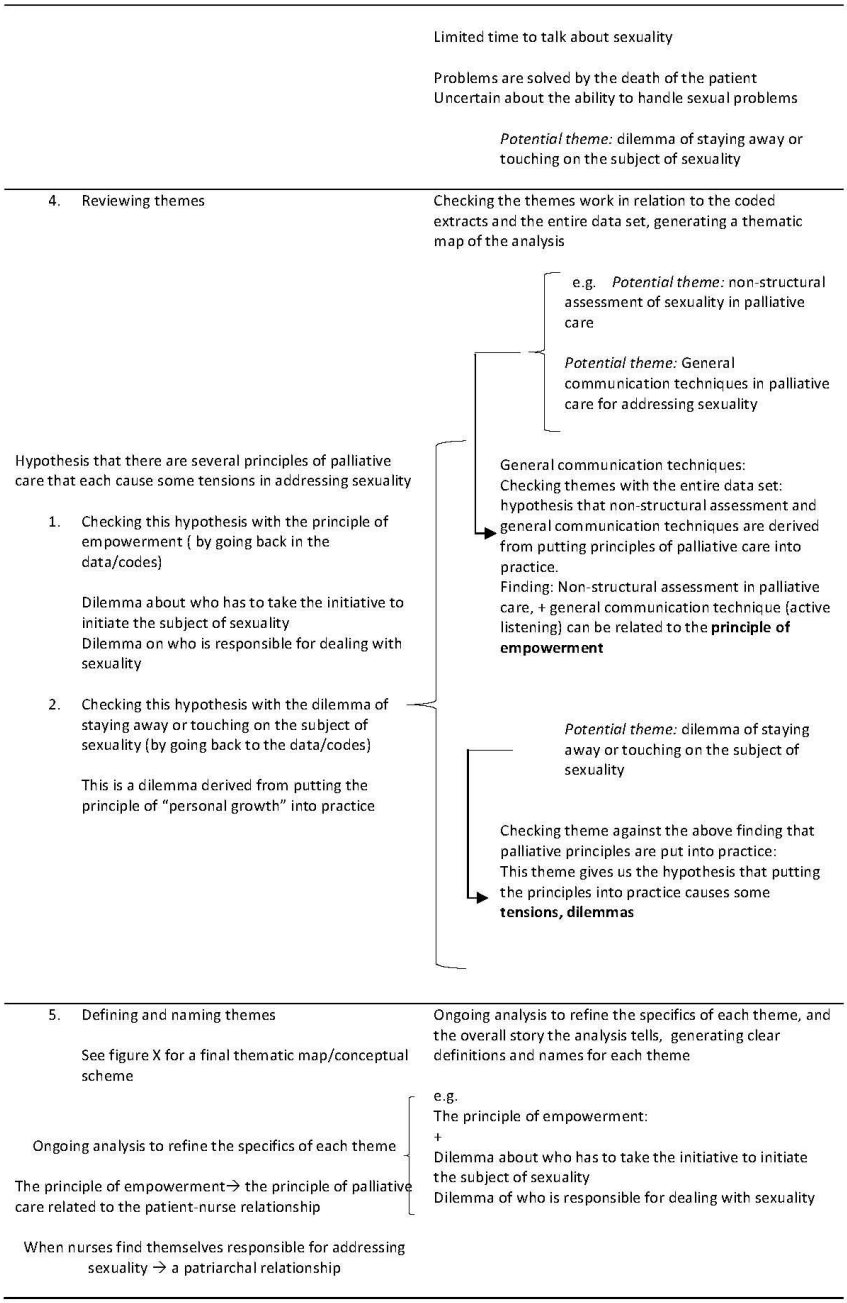
Table 1. Demographics of nurses (n=21)

	Palliative support team	Residential palliative unit	Home care organisation	Palliative day care centre
Male	0	1	3	0
Female	2	5	8	2
Age Range	30-45	32-58	28- 57	40-55

Phase		Description of the process
1.	Familiarising yourself with your data	Reading and re-reading the data , noting down initial ideas (general ideas + specific ideas for coding)
2.	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code e.g. "Actually we listen to the patient and their partner, what they bring up, what they need. And if they talk about things like touch, intimacy, sexuality, we pick up on them. Then we ask more questions... and we might be able to work with it... but we don't have any standard questions in palliative care." *Initial codes for this fragment* No standard questioning in palliative care Addressing sexuality through active listening Being attentive to sexuality-related content during active listening Addressing sexuality depends on what the couple brings to the fore " [working on sexuality] . When I see that someone only has another two weeks or a month maximum to live, we often feel here like, are you going to lift the lid on that and start meddling with things that people might not be able to cope with? Or, say the person dies before it is finished, you sometimes do more harm than good. When people die, it might sound strange, but a lot of those problems just solve themselves, you see." *Initial codes for this fragment* Limited time to talk about sexuality Not taking the risk of bringing up sexuality Uncertain about the ability to handle sexual problems Problems may be solved by the death of the patient
3.	Searching for themes (detailed illustration of the coding tree available in supplementary files)	Collating codes into potential themes, gathering all data relevant to each potential theme E.g. No standard questioning in palliative care Addressing sexuality depends on what the couple brings to the fore Not taking the risk of bringing up sexuality → *Potential theme:* non-structural assessment of sexuality in palliative care Addressing sexuality through active listening → *Potential theme:* General communication techniques for addressing sexuality



When nurses find addressing sexuality a shared responsibility → an empowering relationship	
6. Producing the report	Selection of vivid extract examples, final analysis of selected extract, relating back of the analysis to the research question, producing a scholarly report of the analysis

Table 2: Phases of Thematic Analysis (Based on Braun & Clarke, 2006)

Table 3: List of good practices of palliative care nurses addressing sexuality

Attitude about sexuality

- Seeing sexuality as a part of quality of life in the palliative phase
- Being open to actively explore sexual issues with the couple
- Giving sexuality as much priority as other care needs
- Tackling their own assumptions about the priority of sexuality or their uncomfortable feelings
  - By personal reflection
  - By team reflection

Communication about sexuality

- Probing to help the couple understand what is going on with their sexuality:
  - "Is the sexuality (intimacy) different than before (the illness/the palliative phase/the hospitalization)?" " In what ways has it changed?"
  - "What would you want to change about your sexuality?"
  - "What could you do to change these aspects of sexuality"?
- "Negotiating about sexuality" instead of "giving information about sexuality"
  - Negotiating about putting a hospital bed in the home of the couple
  - Negotiating about the timing of giving pain medication so to facilitate the possibility for intimate moments
  - Active listening
  - Not giving practical advice but exploring the issue together
- Using facilitating techniques to initiate discussion
  - Responding to cues sensitively and respectfully
  - Using humour with the intention to open up, not to close it down

Facilitating sexuality

- Encouraging couple to be (sexually) intimate:
  - Encouraging to have bodily contact
  - Encourage to lie together in bed if possible
  - Encourage to massage, hold hands
  - Encourage to close the door on palliative unit

- Consciously creating an atmosphere that promotes sexual intimacy
  - Adapting hospital infrastructure to facilitate an environment for physical intimacy, e.g. candles, twin-beds
  - Ensuring privacy by knocking the door of the patient's room before entering

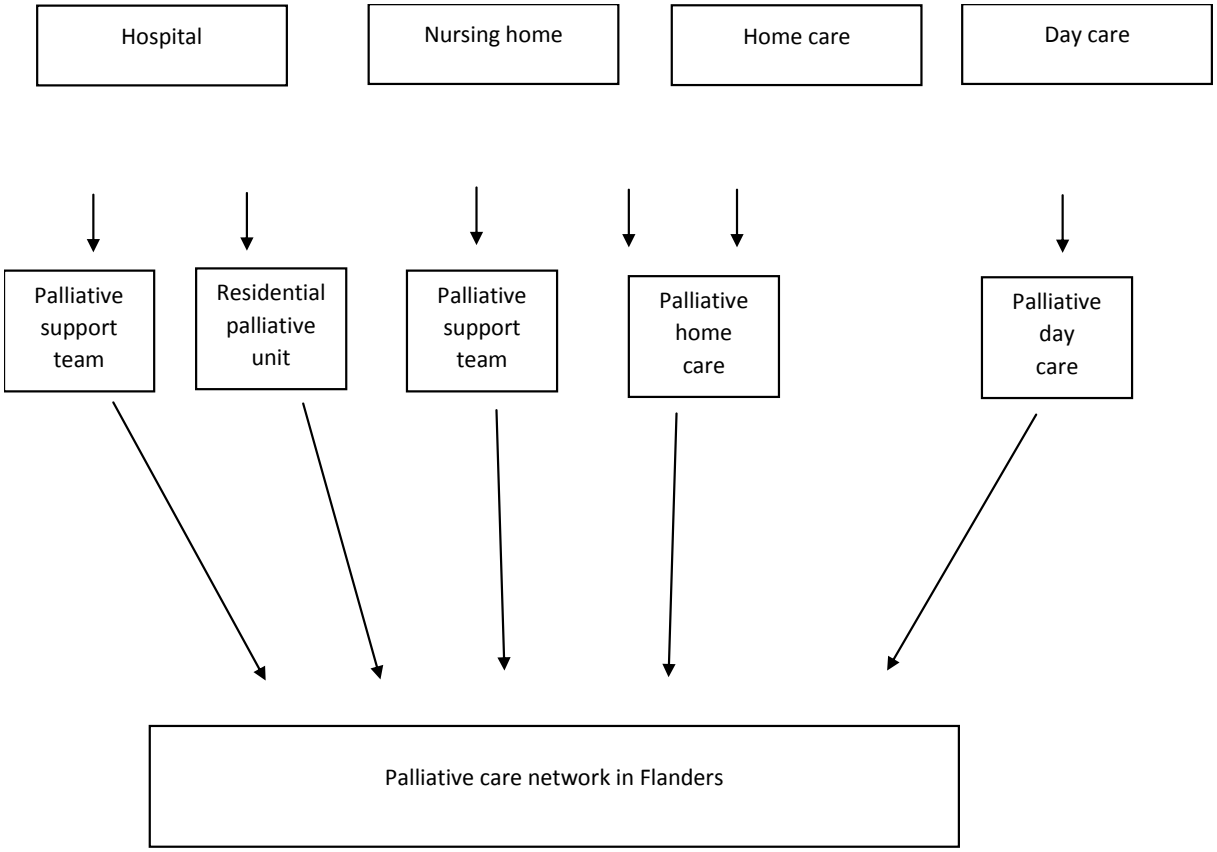


Fig. 1. Organisation of palliative care in Belgium

Fig 2: Phase 5 in thematic analysis: defining and naming themes