

Bereavement Care in General Practice

Aselya Tina Jonette Nielsen, MD, MA Health Anthropology.

University of Antwerp.

aselya.nielsen@gmail.com

Promotor: Mieke Vermandere, MD, PhD.

University of Leuven.

Master of Family Medicine

Masterproef Huisartsgeneeskunde

Abstract.

Context.

Exploring the literature on the causes of "the widow effect", it became apparent that widows with a spiritual belief manage better with regard to grief and depression. This led to the literature search on "spiritual bereavement care", comprising the first part of this study.

The meager result of the literature search and the fact that only a few studies on bereavement care in general practice were found motivated the qualitative inquiry into the ideas and behaviors of GPs regarding bereavement care, comprising the second part of this study.

Research question:

(1) Do spiritual care interventions in widows, delivered within 12 months after the death of a spouse, affect levels of well-being, grief and depression?

(2) What are GPs' perceptions about their role in bereavement care as well as the perceived facilitating factors and obstacles in introducing a model of bereavement care in general practice?

Methods:

(1) Literature review. (2) Semi-structured interviews and the QUAGOL- guide for data analysis.

Results.

(1) No articles were found.

(2) The observed attitudes and behaviors were ambiguous and often contradictory. Heavy schedules and prevailing perceptions of bereavement care as being time - and energy consuming were found to be the biggest obstacles to bereavement care. The almost complete lack of formal training was generally not perceived as a problem, the GPs placing intuition above theory and "learning by doing" above formal training. Four important tasks were identified: recognizing pathology, listening, normalizing the experience and facilitating treatment.

Discussion:

A model of triangulation between (1) the role of the GP, (2) the perspective on grief and (3) the social matrix was developed to explain the observed ambiguities and contradictions.

Conclusion.

Several factors influence the decision making process concerning bereavement care in general practice and the extent to which grief stays "on the radar". A grief compass to support and guide the largely intuitive assessment currently used by the GPs, could ensure consistency, confidence and quality in performing the identified four major tasks of bereavement care in general practice.

Motivation.

This master-project is motivated by my personal interest in how spirituality can be incorporated into medicine. Palliative care being the most obvious point of entry, I studied the literature and became fascinated by "the widow effect", which describes the increased mortality and morbidity after conjugal bereavement. The literature suggests that people with spiritual beliefs somehow manage better after the loss of a spouse, and I decided to perform a literature search to find out if any interventional studies on spiritual bereavement care had been done.

The fact that not a single study was found intrigued me and, paired with my background in Medical Anthropology, led to reflections on what spirituality is and how it maybe does exist within science - although rather incognito because of the prevailing perceptions and terminology used. Reading through numerous abstracts on bereavement care, I couldn't help but notice that only a few studies on bereavement care in general practice had been performed. Notwithstanding my personal interest in spiritual bereavement care, it seemed more logical to find out what the GPs thought of bereavement care in general. Did they even care?

This master-project thus consists of two separate studies, a literature search on spiritual bereavement care and a qualitative study on bereavement care in general practice. They are connected by my personal motivation to bridge the gap between spirituality and medicine and create a sound base for true holistic health care.

Table of content.

Abstract 2

Motivation 3

Table of content 4

Literature Review on Spiritual Bereavement Care 6

Introduction 6

Inclusion – and exclusion criteria 7

Results 7

Discussion 10

Conclusion 11

References 12

Figures and Tables

Table 1. Search strategy 8

Flowchart. Literature selection 9

Bereavement Care in General Practice – a Qualitative Inquiry 13

Introduction 13

Methods 15

1. Research design 15
2. Selection of participants 15
3. Data analysis 16

Results 18

1. Participants 18

2. Content analysis 19
2.0 General observations 19
2.1.0 The model of Triangulation 20
2.1.1 The role of the GP 23
2.1.2 The perspective on grief 25
2.1.3 The social matrix 28
2.1 Guideline versus compass 28
Discussion 30
Summary 30
Strengths and weaknesses 30
Comparison with existing literature 31
Suggestions 31
Conclusion 33
References 34
Figures and tables
Figure 1. QUAGOL 17
Figure 2. The model of triangulation 21
Figure 3. The role of the GP 22
Figure 4. The perspective on grief 24
Acknowledgements 35
Appendix 1 Protocol 36
Appendix 2 Goedkeuring Ethische commissie 37

Spiritual Bereavement Care – evading the researcher's eye?

Introduction

"The widow effect" is described as the increase in mortality in a widow(er) after the death of the spouse. The effect is strongest the first 3 months after the death of the partner but measurable for longer (1). There has been a variation in the effect shown, related both to the cause of death of the pre-decedent partner and the cause of death of the surviving spouse, which suggests several possible factors contributing to the widow effect. The factors can be grouped within the bio-psycho-socio-spiritual framework of palliative care, but are in fact always interrelated (1). Biological factors refer to the shared habits of the couple, which may ultimately have contributed to their deaths, as well as positive habits, which after the death of the partner are difficult to maintain, for example daily walks and cooking (2). Depression is independently linked to the loss of a spouse, but also to increased mortality and loss of social skills, which in turn can lead to social isolation (3). The level of strain experienced in the caregiving leading up to the death of the spouse also influences the risk of depression/complicated grief and conversely inhibits the possibility of personal growth after bereavement (4), stressing that caregiving and bereavement care always occur in a social context, which points to the importance of support from family, health professionals or palliative teams.

Spirituality, understood as a personal search for answers regarding life, meaning and the relationship to the sacred or transcendent (5), has been shown to ameliorate some of the suggested factors in the widow effect. The process of active re-creation of meaning during and after the palliative phase has been shown to reduce the risk of prolonged depression in the surviving spouse, and a study on HIV-positive widowers showed that the expected decline in CD4-count was slowed in men practicing a spiritual belief (6). This suggests that spiritually-orientated coping strategies positively influence the immune system. Although only about five percent of the overall mortality of elderly American married couples is attributed to sepsis and other infections (1), spirituality understood as meaning creation can affect important functions of the body and thus may be seen as a protective factor against the widow effect. For people with a religious belief, the coping strategies are shown to be multidimensional and can be understood as the process of meaning construction, seeking social support in the congregation and maintaining a connection with the deceased (believing in re-union after death, that the spouse watches over them etc.) (7). Although some religious coping strategies have been shown to have a negative effect on psychological wellbeing, more studies point towards a general positive effect, for example the association between higher religiosity and a higher level of personal strength (8)

Most research within the medical field is done with the intent to improve future treatment and care, whether it be on a medical, psychological, logistical or administrative level. The primary quest to understand complex contexts and situations is often followed by an intervention to try and improve the uncovered problems. With the widow effect thoroughly established and the effect of spirituality suggested, it would therefore be interesting to know if there have been any interventional studies done on spiritual bereavement care.

This literature review aims at answering the following question:

Do spiritual care interventions in widows, delivered within 12 months after the death of a spouse, affect levels of well-being, grief and depression?

Inclusion and exclusion criteria.

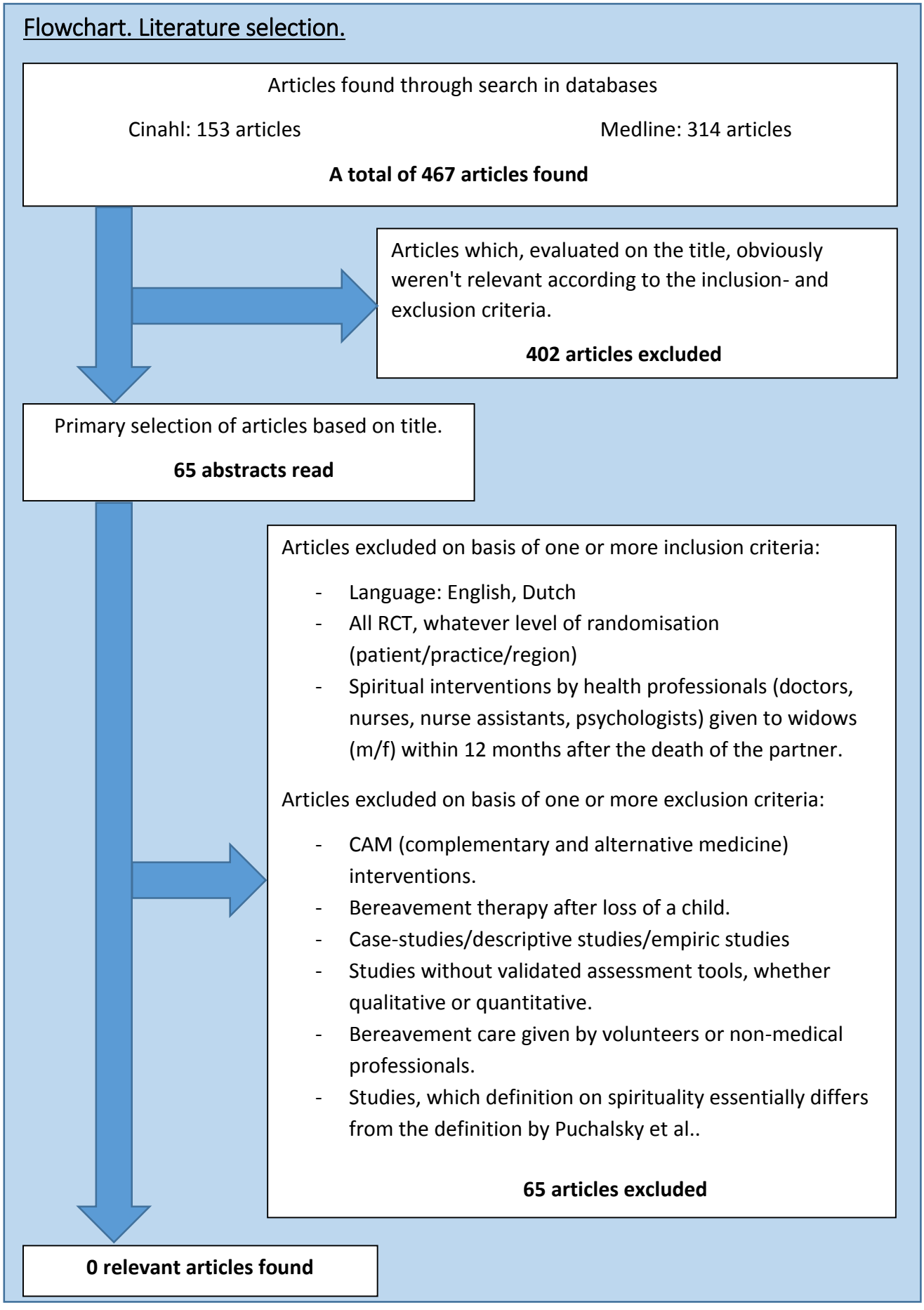
We included articles in English and Dutch. We included randomised controlled studies, whether the control be on an institutional, local or regional level. The spiritual intervention had to be given to widows (m/f) within 12 months after the death of the partner and conducted by health professionals (physician, nurse, nurse assistant, psychologist). Interventions within the field of complementary and alternative medicine were excluded. The evaluation of the intervention had to be based on validated assessment tools, whether quantitative or qualitative. Descriptive studies, empiric studies and case studies were excluded. Interventions carried out by volunteers or non-medical professionals as well as studies concerning bereavement care after the loss of a child were excluded. Also studies which definition of spirituality substantially differed from that provided by Puchalsky et al. (9) were excluded.

Results.

The search (see Table 1) delivered a total of 467 articles, and a preliminary selection was done based on a comparison of the chosen inclusion criteria and exclusion criteria and the title of the article. This left a total of 65 articles, from which the abstracts were read. Applying the inclusion criteria and exclusion criteria, no articles were appropriate for full text examination (see Flowchart).

Table 1. Search strategy. April 2015

Database	Date of search	Search terms
Medline	30/04/2015	spirituality(MeSH) AND bereavement care(MeSH)
Medline	30/04/2015	Spirituality (MeSH) AND bereavement (MeSH)
Medline	30/04/2015	Spirituality(Abstract/Title) AND bereavement care (Abstract/Title)
Medline	30/04/2015	Spirituality(Abstract/Title) AND bereavement(Abstract/Title)
Cinahl	30/04/2015	Spiritual* (Abstract) AND bereavement (Abstract)
Cinahl	30/04/2015	Spiritual* (Abstract) AND bereavement care (Abstract)


Flowchart. Literature selection.
Articles found through search in databases
Cinahl: 153 articles
Medline: 314 articles
A total of 467 articles found
Articles which, evaluated on the title, obviously weren't relevant according to the inclusion- and exclusion criteria.
402 articles excluded
Primary selection of articles based on title.
65 abstracts read
Articles excluded on basis of one or more inclusion criteria:
- Language: English, Dutch
- All RCT, whatever level of randomisation (patient/practice/region)
- Spiritual interventions by health professionals (doctors, nurses, nurse assistants, psychologists) given to widows (m/f) within 12 months after the death of the partner.
Articles excluded on basis of one or more exclusion criteria:
- CAM (complementary and alternative medicine) interventions.
- Bereavement therapy after loss of a child.
- Case-studies/descriptive studies/empiric studies
- Studies without validated assessment tools, whether qualitative or quantitative.
- Bereavement care given by volunteers or non-medical professionals.
- Studies, which definition on spirituality essentially differs from the definition by Puchalsky et al..
65 articles excluded
0 relevant articles found

Discussion.

The outcome of the literature search is intriguing, because of its lack of articles meeting the chosen criteria. Reading through some of the many descriptive studies which were excluded, it is interesting to notice that most of them end up suggesting that more research must be done on the effect of spirituality on the bereavement process and the implications for bereavement care, but in the search only two such studies, interventional but non-randomised, were found (10,11,12). Both describe the same intervention, "The Bereavement Life Review". By making an intervention, choosing to label it as spiritual and measuring its effect, these studies thus take it a step further than merely describing the positive effect of a self-ascribed spirituality on depression and spiritual well-being.

Bereavement Life Review - a short presentation.

The Bereavement Life Review is based on narrative theory, which assumes that the (re)creation of meaning through "story-telling" has a positive psychological effect. The practical execution of the BLR consists of two therapeutic conversations of 30-60 minutes, conducted by a health professional. In the first session a short series of questions is asked to stimulate the narrative process. In between sessions the conversation is transcribed and the information creatively assembled by the therapist into an album, a "life review". In the second session the content of the album is presented and checked with the patient. The method has been tested on populations in Japan and Hawaii and claims to reduce levels of depression and increase levels of spiritual well-being, but the study samples are small and the results not necessarily universally applicable. Without drawing too strong a conclusion from these small studies, I find them interesting because of the association of the healing effects of spirituality and narrative as well as the simplicity of the intervention itself. They demonstrate that spiritual elements can be incorporated into concrete psychotherapeutic tools, which can be standardised and tested.

Recognizing spirituality in scientific discourse.

Intrigued by the lack of relevant articles in the search, and considering the theory behind BLR as well as the relationship between spirituality, meaning creation and narrative theory, I wonder if not any kind of bereavement care, allowing the personal story to be told, (re)interpreted and thus aiding in re-creating meaning, is inherently spiritual? To what degree do the existing modalities of bereavement care facilitate or encourage this meaning-creating, narrative process?

Another point of discussion is the use of the word "spiritual". Even though there are several available definitions recognized within the humanistic and social sciences, a literature search will

only lead to results, if the researchers and publishers recognize the spiritual component in the study and choose to name or label it as such. Kogler et al have published a randomized study on the effect of existential behavioral therapy (with mindfulness training as a core element) in informal caregivers of palliative patients (13). The level of mindfulness was a significant predictor of improvement in psychological well-being three months after the intervention. Whilst I don't intend to discuss the strengths and weaknesses of this study here, I find it interesting, that this particular study didn't show up in my literature search, as one of its main outcomes was "meaning of life". Mindfulness Based Stress Reduction (MBSR) is a method, inspired by the meditation practices from the East, translated, developed and adapted to a Western audience by the now well-known molecular biologist Jon Kabat-Zin. I believe that the success of MBSR throughout the western scientific and general public is due to its claim to be scientifically based, tested through recognized methods with proven results. The association or link with philosophy or spirituality is not always appreciated and can be an obstacle in a society heralding scientific discourse. Spirituality in science is relatively new and although things are changing, I believe some scientists are either not aware of the spiritual aspect of their research or simply choose not to label it as such for fear of ridicule or ignorance from the scientific community. Recognizing the spiritual aspect in science in general and in bereavement care specifically is thus an important pre-requisite for further research.

Conclusion.

The idea for this study arose from on one hand the link between increased mortality in widows and depression and on the other hand the suggested increased psychological resilience in widows with a spiritual practice. The aim of this literature review was to ascertain the effects of spiritual bereavement care on levels of grief, depression and spiritual well-being. Surprisingly, no randomized interventional studies were found. Two non-randomized interventional studies suggested a positive effect on depression levels through the application of the narrative tool named "Bereavement Life Review". This leads to the discussion of whether narrative tools/methods, facilitating healing through re-creation of meaning, are not inherently spiritual. This in turn leads to reflections on, whether spirituality in science for different reasons could be hidden, under-expressed or at least mislabeled. This could be a possible explanation for the negative outcome of the literature search.

References.

1. Elwert F, Christakis N (2008) The Effect of Widowhood on Mortality by the Causes of Death of Both Spouses. *Am J Public Health, vol. 18, no 11.*
2. Espinosa and Evans (2008) Heightened mortality after the death of a spouse: marriage protection or marriage selection? *Journal of Health Economics, 2008; 27:* 1326-42.
3. Moller J, Bjorkenstam E, Ljun, R, Yngwe, M A (2011) Widowhood and the risk of psychiatric care, psychotropic medication, and all-cause mortality: a cohort study of 658,022 elderly people in Sweden. *Aging Ment Health, 15(2):*259-66.
4. Carver C S (2013) Finding benefit in bereavement among family cancer caregivers. *J Palliat Med 16(9):* 1040-7.
5. Koenig, McCullough and Larson (2001) Handbook of religion and health. New York: Oxford University Press.
6. Bower J E et al (1998) Cognitive processing, discovery of meaning, CD4 decline, and aids-related mortality among bereaved HIV-seropositive men. *J Consul Clin Psych 66(6):*979-86.
7. Michael S, Crowther M, Schmid B, Allen R (2003) Widowhood and Spirituality: Coping Responses to Bereavement. *J Women & Aging, vol. 15, no 2/3 2003:* 145-165.
8. Kim et al. (2011) Personal strength and finding meaning in conjugally bereaved older adults: a four-year prospective analysis. *Death Studies, 2011 Mar; 35(3):* 197-218.
9. Puchalsky et al. (2009) Improving the quality of spiritual care as a dimension of palliative care: the report of the consensus conference. *Journal of Palliative Medicine, 12:* 885-904.
10. Ando M et al. (2010) Effects of bereavement life review on spiritual well-being and depression. *J Pain Sympt Man 40(3):* 453-59.
11. Ando M et al. (2014) Bereavement life review improves spiritual well-being and ameliorates depression among American caregivers. *Palliative Supportive Care 10:* 1-7.
12. Ando M et al. (2014) Universality of Bereavement Life Review for spirituality and depression in bereaved families. *Am J Hosp Palliat Care 31(3):* 327-30.
13. Kogler M et al. (2013) Mindfulness in informal caregivers of palliative patients. *Palliative Supportive Care 17:* 1-8.

Bereavement Care in General Practice – a Qualitative Inquiry.

Introduction.

There hasn't been a lot of interventional studies performed within the area of spiritual bereavement care, although the literature suggests that spiritual coping mechanisms could be an important protective factor regarding "the widow effect"(part 1 of this paper). It is not yet the norm to include spirituality in the paradigm of western medicine, fringe-specialties such as palliative care being an exception. Spirituality seems to evade the eye of the medical scientist, although it could be seen as an integral part of the human condition, according to the international consensus definition published by Puchalski et al. (1).

Bereavement care bears some of the same characteristics as spirituality. Although bereavement and grief lies at the heart of the human existence, the management of this "condition" seems to lie at the fringe of the medical profession. Here also, little research has been done. A literature review on bereavement care practices amongst British GPs only found small studies of limited quality, often on single GP practices, or more than 10 years old. The bereavement care provided by GPs varied from condolence letters or phone calls to home visits, which only says something about the form of the bereavement care, nothing about the content. They concluded that GP's find the task of bereavement care important, although they receive little training (2). Another study on bereavement care, including hospital wards, community nursing teams, care homes and GPs, stated that bereavement care depends on an established relationship between health care staff and the patient's relatives and preparation for the relative's death may not equate to being prepared for bereavement (3), suggesting the need for a specific approach after bereavement and that the GP, having an established and continuous relationship with the patient, would be a suitable person to fulfill this task. An Australian qualitative study on bereavement care in general practice identified four tensions or opposing views of the GPs concerning whether (1) grief is a standard versus an individualized process, (2) the role of the GP in intervening versus promoting resilience, (3) the GP as a broker of services versus a service provider, and (4) the need for formal education and professional development versus "on-the-job" experiential training (4). A Danish cluster-randomized controlled trial on bereavement care by GP's with or without formal training suggested that trained GPs to a higher degree than GPs without training preferred supportive care or referral to mental health practitioners over the use of psychotropic drugs and that their patients showed larger improvement in their ICG-R scores (5). Another study, based on a survey of recently bereaved patients in a single GP practice in Britain, showed that most patients expected some sort of contact from their GP and would like to receive bereavement support. More than half of the bereaved showed some sort of dissatisfaction with the GP or the hospital regarding the handling of the death, also suggesting that training could be useful (6).

The medical profession claims to be evidence-based and the research motivated by the needs of the patients. It is thus paradoxical, that so little research has been done in an area so inherently human. Is grief too difficult to grasp, handle and measure to be of interest within the current medical paradigm? Is it low-prestige? Do the attitudes of the GPs simply reflect those of the western society, where death and grief is largely taboo and thus a sensitive area to get involved with?

There are a lot of questions to be answered, but first and foremost it would be interesting to know how the general practitioners in Flanders themselves think about bereavement care. Arguing that the nature of the subject matter lies close to that of spirituality in general practice, there is inspiration to be found in the work of Vermandere et al, who wrote a qualitative evidence synthesis on how GPs think about their role as a spiritual care giver as well as the barriers and facilitating factors of addressing spirituality in general practice (7). Coming back to the initial motivation for this paper, the question whether "the widow effect" could be ameliorated through providing spiritual bereavement care, it would seem logical to ask the general practitioners how they perceive their role in bereavement care, if they would like to have a tool/model to provide bereavement care, and the facilitating factors and obstacles of introducing a model of bereavement care for the recently bereaved. Gaining more knowledge in this area, it could form the basis on which a model of bereavement care for general practitioners could be developed and tested.

The aim of this study is to explore GPs perceptions about their role in bereavement care as well as the perceived facilitating factors and obstacles in introducing a model of bereavement care in general practice to be applied to widow(er)s within the first year of the passing of their partner.

Methods

1. Research design

A qualitative approach, using semi-structured interviews, was chosen as research method.

The topic guide for the interviews was developed with direct reference to the research question:

1) What are your own experiences with bereavement care (for someone who has lost their partner within the last year)? Have you experienced any problems?
2) On what basis do you draw your knowledge and make decisions within the field of bereavement care?
3) How do you see the role of the GP in bereavement care?
4) If a more systematized tool for bereavement care in general practice was to be introduced, which elements would you consider relevant or important?
5) Which factors could stimulate your interest in using such a tool? (content/technical/training/supervision)
6) Which factors could prevent you from using such a tool?

2. Selection of participants

For the selection of interview participants, the method of purposive sampling was used. Without knowing which factors actually influence the attitude towards bereavement care among the GPs, the following rough socio-demographic variables were chosen to facilitate variation:

(1) male/female
(2) above/under 46 years of age (the estimated age of the GPs being half-way through their working years, normally graduating around 27 years of age and the retirement age in Flanders being 65 years of age)
(3) self-employed with a paying clientele/working within the framework of a subsidized practice

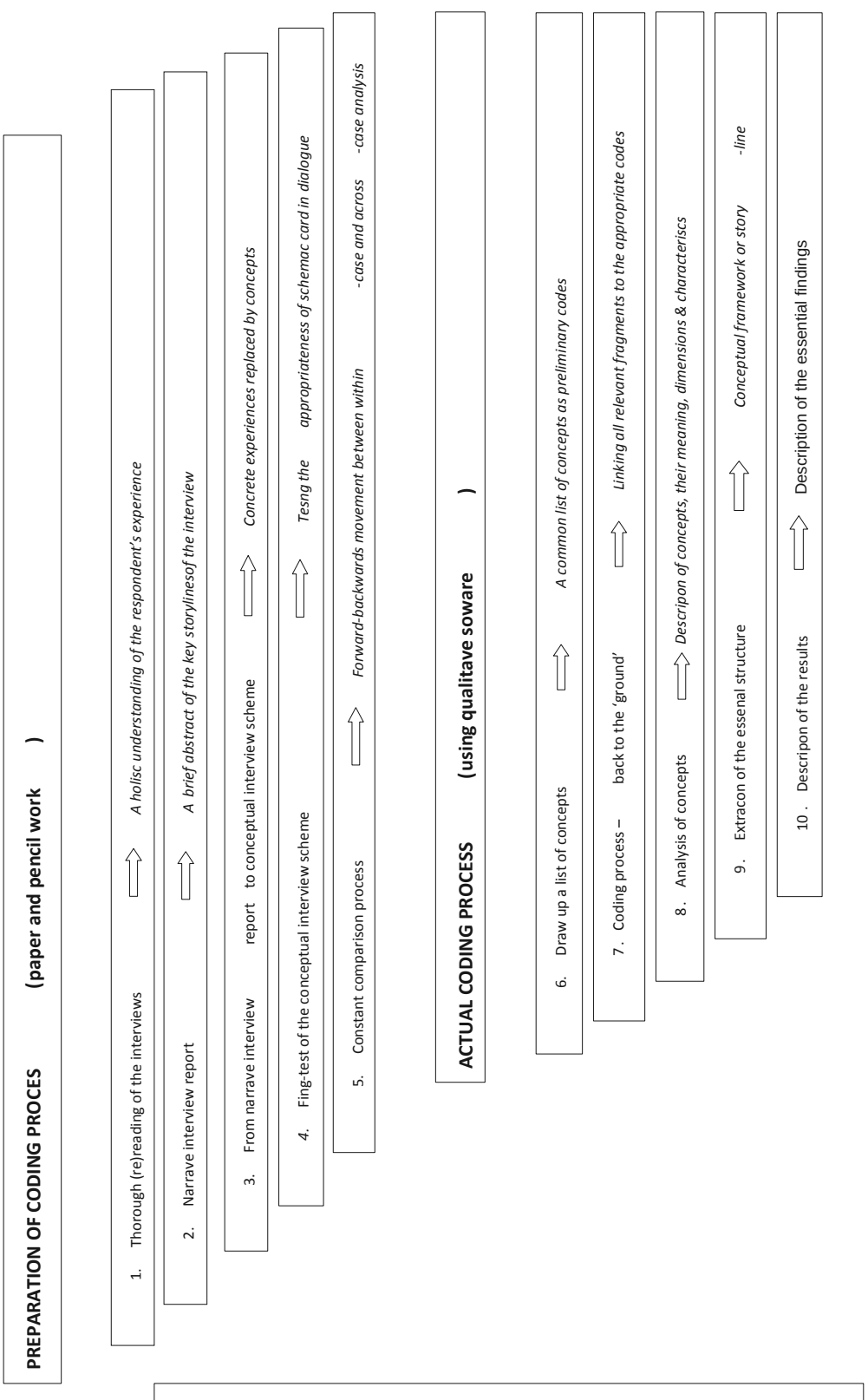
Acknowledging that there are other possible factors contributing to variation in perspective among the GPs, namely the level of heterogeneity of the patients regarding country of origin and whether the practice is located in a city or a village, the above mentioned variables were chosen because they, to a certain degree, include the others. Subsidized practices in Flanders are placed in city-areas with a high degree of patients from the lower social strata, also comprising a higher representation of immigrants than the typical self-employed GP, whether being based in a city or village.

3. Data analysis.

The interviews were recorded and transcribed verbatim and the data analyzed according to the principles of QUAGOL (8).

The Qualitative Analysis Guide of Leuven (QUAGOL) is a comprehensive method to guide the process of qualitative data analysis. It consists of two parts, each comprising 5 stages (box 1). It is characterized by an oscillating movement between analyzing the data, structuring it, returning to the data to check for coherence, digging deeper and deeper, thus ensuring a comprehensive knowledge of the subject matter. As with all qualitative research methods, it serves as a tool to structure the work of the researcher, whereas the actual quality of the work also depends on the personal skills, intuition and creativity of the researcher. QUAGOL emphasizes the research team as an important factor in ensuring the validity in qualitative research. The process of testing concepts and ideas against the collected data and with the other members of the research team reduces the risks of bias or blind angles. The arguments for working in a team are applicable to all qualitative research, no matter the method, so being aware of the limitations of working as a single researcher on this project, the QUAGOL method was chosen for its methodological assets (Figure 1).

Figure 1. QUAGOL.



Results.

1. Participants

Some difficulties in the recruitment of interview participants were expected, based on previous experiences of fellow researchers in qualitative research (7). The recruitment was indeed cumbersome, and the following are perceived as possible contributing factors:

1) Work-load of doctors, making it difficult to spare time for a research project.
2) The subject matter being a possible "fringe-subject" to some doctors, not stimulating sufficient interest (for spending their time on it).
3) Work schedule of researcher, which had to be coordinated with those of the doctors.
4) This leading to a limited geographical distribution of the possible participants.
5) Researcher having an inferior position as a GP in training, which could lead to a lack of appreciation and/or respect from some of the more senior colleagues.
6) The interviews had to be conducted in Dutch (the researcher doesn't speak French), which excluded a number of possible doctors from the subsidized practices in and around Brussels.
7) Set-up of study, regarding the 8 chosen demographic sub-groups (according to gender, age and organization of the practice). Some categories were more difficult to recruit, especially the "male, under 46 years, subsidized practice".

Data saturation was achieved after 15 interviews. The successful recruitment of interview participants was largely due to the inter-professional network of the researcher and her current and former colleagues. The selection of participants is thus exactly that – a pre-selection of approachable and available doctors from the local network of the researcher and her colleagues (table 1).

Table 1. List of participants.

Participant	Gender	Age Group	Practice set-up
1	Male	>46	Subsidized
2	Female	<46	Subsidized
3	Male	<46	Self-employed
4	Female	>46	Subsidized
5	Female	<46	Self-employed
6	Female	>46	Self-employed
7	Female	<46	Subsidized
8	Male	<46	Subsidized
9	Female	>46	Self-employed
10	Male	>46	Self-employed
11	Female	>46	Self-employed
12	Male	<46	Self-employed
13	Female	<46	Self-employed
14	Male	<46	Self-employed
15	Male	>46	Subsidized

2. Content analysis.

2.0 General observations.

What characterizes the interview data is a general sense of ambiguity and contradiction as well as quite different attitudes towards grief and the role of the GP in bereavement care. Most GPs seem to have a positive attitude towards assisting their patients through their grief, some of them even consider it one of the major tasks of being a GP, whilst others think that the role of the GP is and indeed ought to be very limited in the processing of non-pathological grief. In reality the GPs vary very little in their practical approach. Most GPs are aware that they don't have a lot of theoretical training within this area, which in some of the younger doctors leads to self-doubt as to what extent they could and should be assisting people in mourning. Paradoxically they haven't been trying to look for the missing information, not in books, training or guidelines. The doctors with more experience feel generally confident in performing a basic level of bereavement care, but paradoxically lack any sound theoretical basis for doing so. Still most of them are convinced they

are doing a good job. These contradictions seem perplexing at first, because they don't reflect the expected professionalism of the GP.

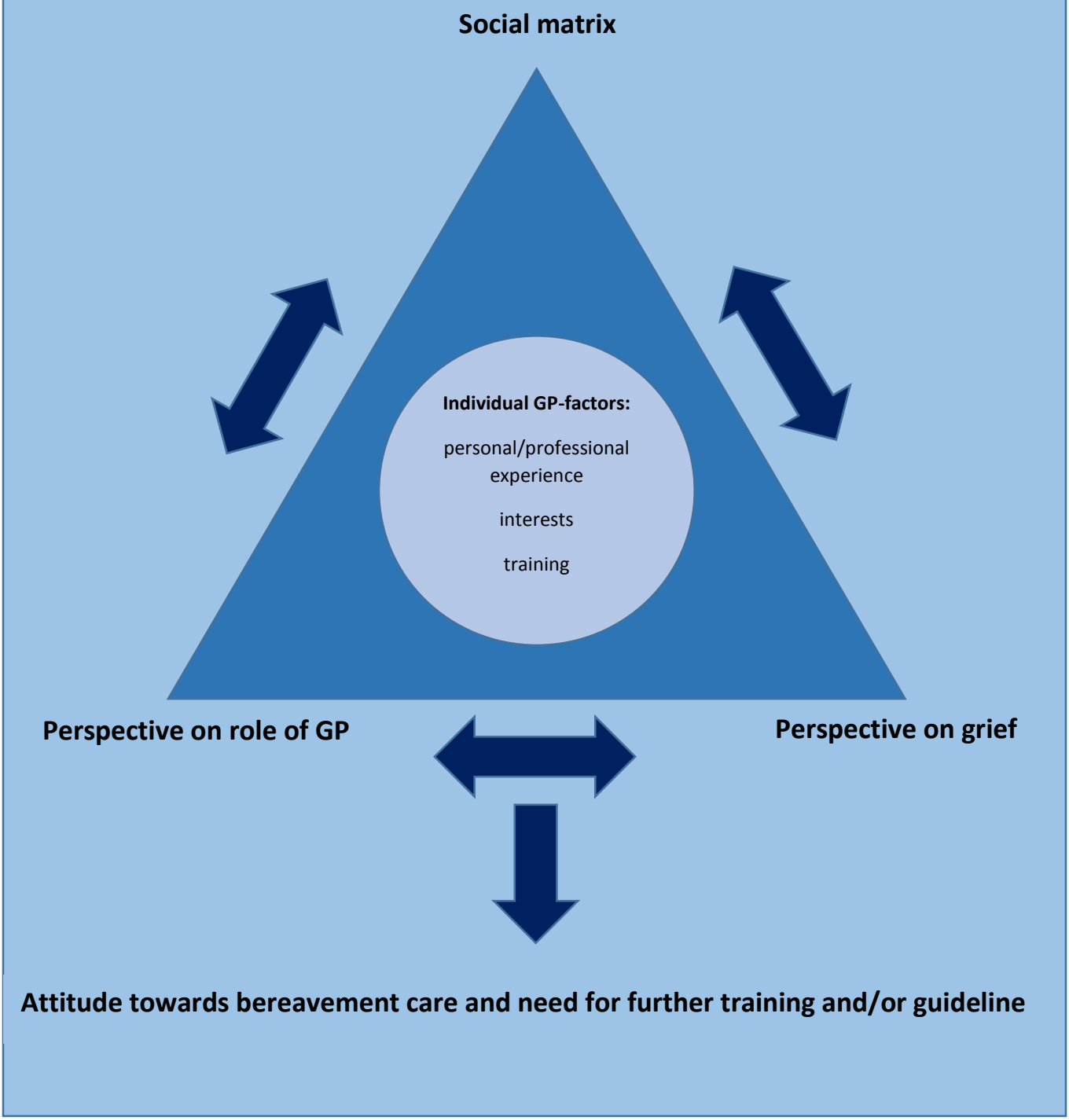
The attitudes to introducing a tool for bereavement care by the GP also vary, but somehow seem to reflect the same variation of basic perspectives on grief and the role of the GP in bereavement care. Some doctors are simply against introducing any kind of tool, because it medicalizes something which they perceive as normal, whilst other doctors would like to have a tool to navigate more confidently within the area of bereavement care. In general there is a strong aversion against questionnaires, check-lists, complicated theories and any kind of guideline on paper – whilst a short, practical and digital tool which allows for intuitive feel and personal judgement is more welcome. GP's are busy people and because bereavement care is generally viewed as "expensive" regarding investment of time and energy, a tool which adds to this perceived burden is not likely to be used.

During the analysis of the data, most of the observed contradictions appeared to be centered on different perceptions of what it means to be a GP as well as the significance of grief. The respective roles of the GP and the patient also seemed to be strongly influenced by the social matrix. The following model of triangulation has been developed as a conceptual framework for understanding the GPs' attitudes and behaviors concerning bereavement care. Whilst on one hand being steadily anchored within the data, it can also be seen as the first step towards a higher level of abstraction, stimulating reflections on what influences human behavior in general and professional attitudes specifically.

2.1.0 The model of triangulation.

The observed variations and contradictions in perspective and behavior amongst the GP's can be explained using a model of triangulation between (1) perspective on the role of the GP, (2) perspective on grief and (3) the social matrix (Figure 2). Most GPs were not conscious of one or more of their positions at the beginning of the interview, and for some of them the interview itself lead to more awareness about their perceptions and how they were sometimes not congruent with their practices. The model of triangulation is of course a simplification of the reality, and the three parameters are mutually influencing each other, just as the individual personality and life experience of the GP also flavors the attitude towards bereavement care. Bearing this in mind, the following sections will explain the three parameters, whilst at the same time illuminate the actual practices of the GPs.

Figure 2. Model of triangulation.



2.1.1 The role of the GP.

> *"It is not a pathology, and thus it doesn't belong to me, I think. It is only if it becomes pathological, if it evolves into a depression, that it belongs to us" (P11).*
>
> *"For me it is an important part of my practice, it is something inherently related to my profession. Others may think differently about it" (P09).*

The above statements come from two self-employed female GP's, both with around 20 years of experience. They illustrate the observed variety in perspective on the role of the GP, which is comprised of a continuum ranging from "the GP as a human being", over "the GP as health coach/support" to "the GP as professional" (Figure 3). Every GP positioned himself/herself somewhere along this continuum, sometimes not consistently.

Figure 3. Continuum of perspectives on the role of the GP



The GPs thinking that they could and should perform some sort of bereavement care seemed to be willing to a larger extent to include interpersonal skills and "being human" as part of their professional make-up. Whether the grief was pathological or not was not as important as the fact that their patient was suffering. Because of the general lack of theoretical knowledge and training in bereavement care, some doctors wanting to employ themselves in this manner refrained from doing so, often not knowing what to do, what would possibly make a difference, when to listen and when to intervene. There seemed to be a schism between how they would like to see themselves and how they reacted when in the situation. This could explain some of the observed contradictions, for example stating that it was an important task for a GP to be of assistance to a grieving patient, but always postponing the question about how the patient was coping until the very end of the consultation. Some of the younger GPs expressed that they wanted to "do well", but their lack of experience with just "being with the patient in their pain" made them feel uncomfortable, which often lead to a referral to a "professional". This seemed to be of less importance with the older generation of doctors, which through professional and personal life

experience had developed more self-confidence in their role as "a human support" and largely used this experience to guide their often intuitive assessment of the severity of the grief. Both younger and older doctors expressed satisfaction when they managed to successfully apply themselves in this manner, wanting to make it a priority. The daily organization of their work and time pressure seemed to be the biggest obstacle, more for the older GPs with similarly older patient populations.

The GPs primarily concerned with diagnosing and treating pathology would in general be more hesitant to initiate a talk about grief, unless they suspected that something was not right, that the grief was turning pathological or into a depression. By sudden or dramatic deaths they would also initiate contact with the relatives, the loss becoming an acute situation with perceived immediate need for intervention and support. These doctors seemed to see themselves more as "doctors in action" than "doctors in being", again emphasizing diagnosing and treating pathology. Because of the above mentioned general lack of theoretical training this group of doctors would often choose to refer the patient with a suspected depression or pathological grieving process to a specialist, with starting an anti-depressant as an alternative option.

One younger doctor explained that she handled grief as she would handle any other health problem as a GP:

> *"I am somebody you can fall back on. I don't know everything, but I will help you. I am the first person you come to, and I will now try to help you or to refer you to someone who can. That is how we work, I think". (P02)*

This perspective can be seen as being "in between" the human and the professional stances. The GP has her very own position, dealing with varying degrees of human suffering and pathology, depending on her own professional and personal competences. The position of being "in between" is traditionally perceived as being problematic within the field of anthropology (9,10) and this is also reflected within and amongst the GPs in the sometimes contradicting schism between the priorities of being human and being professional. The notion of "the GP as health coach/support" may represent the more modern approach to the profession, where the GP with the new emphasis on prevention informs, supports and guides the patient to make informed decisions concerning their health.

2.1.2 The perspective on grief

> *"I think that it is important to listen and to tell the patient that it is perfectly normal, that they don't have to worry and just give themselves the time and space to grieve".(P03)*
>
> *"I think that is it dangerous to label patients as "high risk" – does it then mean that other patients are "low-risk"? It is really an individual thing". (P07)*

When asked about their approaches to grief and how to gain knowledge and experience within this area, two major ideas about grief seemed to prevail, namely *grief as universal human experience* and *grief as unique personal experience* (Figure 4):

Figure 4. Continuums of perspectives on grief.



Grief as universal human experience — Grief as unique personal experience

Paradoxically, both perspectives could be contributing to the lack of professional interest in grief by the GPs. On one hand, some doctors perceived grief as something so inherently human, something that everyone must go through, that it could not possibly be seen as a medical condition. Grief was normal, and thus not the business of a doctor. On the other hand, some doctors perceived grief as something so inherently personal, so intimate and unique to the person experiencing it, that it was impossible to predict its manifestations, severity and duration. Any attempt to generalize or theorize about grief would lead to a risk of failing to recognize a person grieving in a different way. These ideas about grief seem to reflect those of the general population, and some of the GP's expressed concern that some people were not seeking help because they were "just sad, not sick". Hypothetically, if grief was perceived as being somewhat less universal it would form a better study object, if it was perceived as less unique it would be worth forming a theory about. In fact, the study object of grief theory exists, but places itself in "the gap" between the two major perceptions of grief as being universal and/or unique, and as such easily evades the attention of a medical profession preoccupied with pathology and evidence based medicine.

The above mentioned perspectives on grief could account for one of the most intriguing paradoxes observed, namely being aware of lack of knowledge and yet not looking for ways to fill the information gap. Most GPs admitted to having limited or no formal training concerning the normal grieving process, and yet they presented fairly strong ideas about what was normal or not. Most of them vaguely, but not always correctly, referred to the five stages of grief described by Kubler-Ross, but were not aware of the more current developments within grief theory. When asked about the need for a diagnostic tool or a guideline on grief, most of them where not even aware if something of this sort already existed – they had never felt the need to look it up. The perceived duration of normal grief ranged from three to 24 months, presented with equal conviction but based on intuition rather than scientific evidence.

> *"We haven't really had any good training in this, but I also think that it is something that you must learn. I don't think you can learn grief counselling through trainings… I believe that the learning only really begins when you step out into the field of work". (P12)*

When asked about how they had acquired the skills necessary to deal with persons in mourning, most GPs said that it was a matter of "learning by doing". The personal skills required, the ability to listen, to assess risk factors or identify "red flags" all came through experience, sometimes through asking advice from the GP-trainer or a colleague with more experience in this field. Some had asked advice from the multi-disciplinary palliative teams, one doctor mentioned a post-graduate lecture on preliminary planning of end-of-life care, yet another was convinced the needed empathy was developed through reflecting on one's own experiences with loss. The lack of formal training was often not experienced as a problem, the younger GPs also being quite satisfied with their general training in communication, including consultations with surrogate patients.

> *"There are often people, who are so broken that they don't have the strength to get back up, and those people we don't see in our consultation. Maybe the family sees it, or the neighbor, but there is a risk that they are forgotten". (P04)*

The different perceptions of grief also seemed to cause ambivalence or uncertainly as to whether or when to initiate contact with the bereaved. The GPs all used the cultural framework of death (a letter of condolences and a visit to the bereaved household within the first weeks) to let the grieving person know that they were available whilst at the same time making a "risk assessment". Sometimes this had already been done prior to the death of the patient, as the GPs in general perceived the ideal bereavement care as a natural part- and follow-up on the often intense period

of palliation. Most GPs then left it up to the bereaved to initiate further contact if needed. However, some of the more experienced GPs were aware that there was often a difficult period a few months after the death of the partner, when all the practicalities were settled and the loneliness became more prominent. They were also aware that the patients suffering the most often couldn't ask for help. Still, they didn't have a strategy for dealing with this. They seemed to be caught in the schism between wanting to alleviate suffering and not being sure if they had the mandate to initiate contact. Several GPs expressed the importance of respecting the autonomy of the patient and not imposing themselves on the bereaved. By emergencies or severe pathology the GPs felt more comfortable to initiate contact and even force treatment, which explains the feeling of the GPs that they should be present during palliation and after sudden deaths. The perception of grief as something universal could contribute to this hesitance and explain the paradox of the GPs being aware of their patients suffering and yet not trying to create a systematic approach to alleviate it. The most used strategy was that of "opportunistic waiting", which allowed the GP to inquire about the grief process if the patient came to see her for another health problem. Most GPs were quite satisfied with this approach, but admitted to sometimes forgetting to ask. The awareness seemed to easily disappear with the immediacy, and only a couple of GPs were trying to deal with this problem by systematically registering grief in the electronic medical file or in the agenda.

> *"If I sense that the functionality deteriorates, that the patient is heading towards a depression, then I will push more (towards seeking help). Or if there seems to be little support from the surroundings. If they say "I have a sister who comes to visit me and makes sure that I get out of the house", then I feel more at ease".(P02)*

Some GPs adhering to the perspective of grief as being unique and thus unpredictable were opposed to the idea of listing risk factors in a guideline, mainly out of concern that some patients would not fit this pattern and yet need extra attention. However, most GPs more or less consciously seemed to use their knowledge of the patient and the context to assess the risk of pathological grief or depression, using the personality of the patient, the quality of the marriage, the level of social support from friends and family and the cause of death (whether expected, sudden or violent) as parameters. One doctor saw death by euthanasia as an independent risk factor, especially in the older generation brought up within the Catholic belief. Again, all of the GPs based their risk assessment on intuition grounded in experience rather than theory.

2.1.3 The social matrix.

> *"I think that the GPs generally have a feeling of an overloaded agenda. If I have had five patients in a week with double consultations, I sometimes get a little irritated. Sometimes I have two or three in a day. That makes a big difference; it means that you see three less patients that day. Ok, that is what it is, but at the end of the day it also costs you a lot more energy". (*P14)

The role of the GP is intimately related to the society in which the GP functions, and as such the social matrix shapes not only the social role or expectations to the GP, but also the possibilities and limitations on a practical level. The primary health care in Flanders is largely subsidized by the government, but most patients still have to pay the GP after the consultation (the biggest part of the amount will later be reimbursed). Although both patients and GPs are now financially stimulated to make a global medical file (a yearly contract between a particular GP and the patient) to ensure continuity and coordination of treatment, there is still a smell of "the free market" in the air – the patients can chose any doctor they like and can change if they don't like the service. The GPs are primarily paid by consultation and the system of subsidization doesn't discriminate between an ear infection and psychological counselling. The GPs must find their own way in this field of often opposing financial and professional interests. What makes Flanders interesting is that a fully subsidized "pay per patient" – system exists parallel to the more common "pay per consultation"-system. Even more interesting, GPs from either system thought that "the others" would be less motivated to give the time to bereavement care, either out of "laziness" (lack of financial incitement to service the patient) or "greed" (one grief consultation would take the time of two or three uncomplicated, somatic consultations).

> *"I get really stressed, if I know there are three people sitting in the waiting room. I wish I had more time".* (P05)

The GP's all expressed a sense of being under pressure, mostly expressed as coming from heavy schedules, but in some GPs also expressed as coming from the sort of work they were doing. Psychological counselling was by some perceived as heavy as well as time consuming, and one GP explicitly said that in order to prevent a burn-out he tried to limit the number of psychological consultations per day. The constant flow of patients with more or less urgent somatic complaints was by several GPs seen as an important contributing factor in pushing grieving patients off the radar or being something which could be postponed and often ended up being forgotten. This happened even for the GPs who stated the importance of delivering holistic health care to the

patients. Most GPs realized during the interview the possibility of how they could use the electronic medical file or the agenda to raise the awareness of grief in their daily practice.

> *"I think that the important thing about the GP is that he has followed the process leading up to the death of the patient and he has often also declared the patient dead. There is a relation of trust between the bereaved and the GP, a relation from before the death of the patient".* (P08)

The social matrix formed not only obstacles but also facilitated bereavement care by the GP. Accessibility seemed to be poignant in distinguishing the GPs from other professionals involved with bereavement care. The GPs believed that most people were still afraid of the stigma associated with seeing a professional for psychological problems, and that patients often disguised the need for a talk behind a physical complaint. Meeting your neighbor in the waiting room of the GP was on the other hand socially acceptable. The GP saw themselves as being more accessible than specialized psychologists/therapists, both geographically, financially and concerning waiting time. The threshold for the patient to seek help was thus lower by the GPs, which made them ideal for primary psychological interventions, including bereavement care. Combined with the continuity of care, the dual "human-professional"-quality described above and the resulting bio-psycho-socio-spiritual knowledge of the patient, this gave the GP a privileged position to take on a task such as bereavement care. The GPs were aware of this unique position of trust, responsibility and authority, experiencing themselves as facilitating healing through listening, giving attention, sharing the grief, normalizing the experience, explaining the cause of death, showing support and being the "expert" on death and grief, physically, emotionally, existentially and practically. More than one described their function as being "the modern pastor", but although they all recognized this aspect of their work, the extent to which the made room for it in their daily practice varied.

2.2 Guideline versus compass – triangulating the need for a bereavement tool.

> "The idea is to raise the intuitive knowledge to a higher level (P15)"

The model of triangulation influencing GP attitudes and behavior concerning bereavement care helps in understanding their observed ambivalence towards a guideline/support tool. The GPs perceived their main tasks to be *discovering pathology, listening, normalizing the experience,* and *facilitating treatment*.

Discovering pathology was seen by all GPs seen as being very important. To differentiate between normal grief, pathological grief and depression they used the term "functionality" as the most important variable, consisting of elements from eating, sleeping, vague somatic complaints, taking care of yourself and the household to getting out of the house and the ability to function socially. Time was also used as a diagnostic tool, sometimes in the form of a specific duration but more often as evaluating the progression of functionality over time.

Listening was used both as therapy and diagnostic tool. Most doctors were aware of the healing properties of being able to tell the story repeatedly, although the word "narrative" was never used.

Normalizing the experience was important in order to support the patient and validate the often contradictory feelings and experiences related to the grieving process.

Facilitating treatment was also perceived as important, whether they chose to start medical or psychological treatment themselves or to refer to a psychologist/psychiatrist.

On one hand the GPs were aware of their theoretical shortcomings and most of them would like to have a tool to help them discriminate between normal grief and pathology.

On the other hand they often seemed to resist the notion of "guideline", stressing the uniqueness of the grief experience, giving their intuitive assessment priority over theory.

Also, a possible tool/training had to be easy to implement in their everyday work and therefore digital, easy to find, easy to use, not too detailed and not too time-consuming. The same was expressed concerning a possible training on bereavement care - it had to be possible to do on a normal educational evening and some suggested it to be part of a training in palliative care or general communication whilst others expressed no need for a training or doubted the motivation of their colleague to attend.

When asked what they would like to have to aid handling patients in grief, one GP explicitly mentioned a "grief compass", something to help guide their largely intuitive navigation within this field. Another GP called it "a model for your own model", a third said "something to raise our intuition to a higher level" and these notions capture the essence of what the GPs would like – a tool which assists them in performing their tasks efficiently and at the same time allows them to use their intuition and personality to create their own style of bereavement care.

Discussion.

Summary.

At first sight the attitudes and behaviors of the GP's concerning bereavement care seems confusing and often contradictory. This can be understood by using a model of triangulation between continuums of *perspective on grief*, *the perspective of the role as GP* and *the social matrix*. All GPs more or less consciously positions themselves along these continuums and are influenced by the cultural and socio-economic context in which they have to practice. Because the role as GP oscillates between human and professional aspects and grief evades being a study object, being either too universal or too unique, it creates ambiguity. According to anthropological theory, areas which are not clearly defined, things existing "betwixt and between" are culturally considered taboo (Douglas, Mary, 1966) Without claiming that the role of the GP or grief as such perfectly fit these criteria, the theory can serve as an inspiration to understand how grief seems to slip from the consciousness of the GPs and explain the ambiguous attitude of the GPs towards their own role in bereavement care. Undeniably the social matrix also plays an important role by shaping the cultural expectations and the socio-economic context in which the GP must work. Add personal touch and personality to this concoction and the resulting possible attitudes towards bereavement care become indeed multiplex.

Strengths and weaknesses.

The greatest strength of this study is that is goes beyond a mere description of the behaviors of the GP's by deciphering the beliefs, concerns and attitudes behind them. It then suggests a possible conceptual framework in order to explain the apparent complexities and contradictions of these behaviors and attitudes. This is mainly ensured through using the QUAGOL, a comprehensive and well-tested methodology within the field of qualitative research. Also, the researcher's background in medical anthropology facilitates the application of multidisciplinary perspectives.

Within qualitative research, the researcher must always consider his/her own socio-cultural position, because it influences the level of access to the field as well as the extent and manner of which the participants interact and communicate with the researcher being present. The fact that the researcher and the participants are all doctors can be viewed as positive as well as negative in the matter that the inherent familiarity on one hand eases the flow of conversation but on the other hand increases the risk of bias and blind angles concerning the obvious daily routines and shared professionalism of dealing with patients. Also, because the recruitment of participants was accomplished through using the professional network of the researcher and her colleagues, this

could have led to selection bias regarding attitudes towards professional identity, values and socio-economic orientation.

Ideally, qualitative research is carried out by a research team, which helps to develop and test theoretical ideas as well as share the workload from recruitment of participants, conduction of interviews, coding and analyzing the data. Working in a team is the best way to minimize the risk of bias and ensure validity. The aim of this study was to discover the behaviors and beliefs of the GPs concerning bereavement care, and although this has been achieved, a larger study conducted within a team would have allowed for more interviews and detection of a possible variation within the sub-groups.

Comparison with existing literature.

The results of this study are largely consistent with the findings of Nagray and Barclay, which concludes that the GP's find the task of bereavement care important, although they receive little or no training (2). This study adds nuance to the former findings by describing a variation in the attitudes and behaviors as well as trying to explain the observed complexity. The GP's interviewed seem to agree that one of their biggest assets in delivering bereavement care is their multifaceted knowledge of the patient, especially if they were involved in the palliation of the deceased partner. This is consistent with the findings of Stephen, Wilcock and Wimpenny, which stress the importance of an established and continued relationship between the health care worker and the person receiving bereavement care (3). Their notion that preparation for death doesn't equal preparation for grief suggests that there might be a gap of awareness concerning bereavement care, and the results of this study supports as well as suggests a possible explanation for this. Lastly, this study reproduces two of the four tensions/oppositions described by O'Connor and Breen, namely the perspective on grief as a standard versus an individualized process and the need for formal education versus "on-the-job" training (4).

Suggestions

Understanding the triangulation as well as the four main tasks of the GPs (discovering pathology, listening, normalizing the experience, facilitating treatment) helps to explain their ambivalence about a guideline/training, but also makes it clear why there should be one. Through combining experience with theory, the tasks of normalizing the experience, diagnosing pathology and facilitating treatment could be performed with more confidence and consistency.

To increase the likelihood of the GPs using a tool and/or attending training on bereavement care, this has to be structured within and fitted to the already existing modus operandi of the GPs. This

means developing a digital *grief compass*, which through an outline of the basic grief theory combined with diagnostic markers, tips on communication as well as suggestions for treatment and/or referral options would help the GPs navigate the field of bereavement care. Training would ideally consist of the same components, emphasizing communication training as well as a discussion on how to increase the awareness of grief in their daily practice, for example by consistently registering the death of a relative in the patient's digital medical file or in the agenda.

This study shows that GPs through experience gradually develop an intuitive approach to bereavement care, often lacking the theoretical basis for understanding about what works and why. Less experienced GPs have yet to develop this confidence and find it difficult to ascertain whether they are helping the patient or not. A supportive tool highlighting the efficacy of facilitating a narrative process/reconstruction of meaning through simple communication techniques such as attentive listening could make this group of GPs feel more comfortable about taking on bereavement care themselves.

Conclusion.

Interviewing GPs about their ideas and practices around bereavement care revealed initially ambiguous and contradictory answers, on one hand stating importance to the subject matter and simultaneously not having a systematic approach for dealing with it.

The key to understanding their behavior seemed to lie in the interplay between their perception of *the role of the GP*, *their ideas about grief*, and *the social matrix* in which they practiced. A model of triangulation was developed to illustrate how these factors influence the decision making concerning bereavement care, whether the GP is aware of this or not.

Four major tasks of the GP performing bereavement care were identified: *discovering pathology, listening, normalizing the experience* and *facilitating treatment.*

Although their perception of normality varied, all GPs used *functionality* and *time* as the most important factors in assessing the severity of the grief. Their discrimination between normal or pathological was largely based on intuition rather than theoretical knowledge.

The ambiguity about dealing with bereavement professionally was also reflected in their attitudes towards a possible guideline or bereavement tool. A *grief compass*, outlining basic grief theory, red flags, and tips on communication and allowing room for intuition was welcomed. Because bereavement therapy in general was perceived as time- and energy consuming, a bereavement tool was only acceptable if it was compatible with their daily work routines and eased rather than added to their workload.

This study concludes that the development of a grief compass for GPs, providing a theoretical platform to support their intuitive knowledge, could indeed lead to a more consistent and systematized approach to bereavement care as well as aiding the GPs in performing the four major tasks of bereavement care.

References.

1. Puchalski et al. (2009). Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *Journal of Palliative Medicine, 12*, 885-904.
2. Nagray S and Barclay S (2011). Bereavement care in primary care: a systematic literature review and narrative synthesis. *Br J Gen Pract. 2011 January; 61*(582) 42-48.
3. Stephen AI, Wilcock SE and Wimpenny P (2013). Bereavement care for older people in health care settings: a qualitative study of experiences. *Int J Older People Nurs. 2013 December; 8(4):* 279-89.
4. O'Conner M, Breen LJ (2014). General Practitioners' experiences of bereavement care and their educational support needs: a qualitative study. *BMC Med Educ. 2014 March 27*;14:59.
5. Guldin MB, Vedsted P, Jensen AB, Olesen F, Zachariae R (2013). Bereavement care in general practice: a cluster-randomized clinical trial. *Family Practice 2013 April 30(2):* 134-41.
6. Main J (2000). Improving management of bereavement in general practice based on a survey of recently bereaved subjects in a single general practice. *Br J Gen Pract. 2000 November; 505460:* 863-6.
7. Vermandere M et al. (2011). Spirituality in General Practice: a qualitative evidence synthesis. British Journal of General practice, 2011.
8. Dierckx De Casterlé B et al. (2012). QUAGOL: a guide to qualitative data analysis. *International Journal of Nursing Studies 49* (2012) 360-371.
9. Douglas, M (1966). Purity and Danger.
10. Turner, V (1967). The Forest of Symbols.

Acknowledgements.

First and foremost I would like to thank my promotor Dr. Mieke Vermandere for her enthusiasm for my ideas and her focus on structure in the research process. I appreciate the way she relentlessly kept me from wasting too much time on brilliant ideas not relevant to the research question.

I would also like to thank my former GP-trainer Dr. Mieke Peeters and all my current colleagues at Geneeskunde Voor Het Volk in Lommel for many inspiring discussions on how to provide the best possible multi-faceted patient care.

I would like to thank the participating GPs, who were willing to share their time and ideas about bereavement care – I feel privileged to be given the opportunity to learn from their accumulated experience.

A big thanks to Maggie Wilkinson for proof-reading the manuscript.

Last but not least I would like to thank my friends, family and tango-partners, who have shown support and understanding in numerous ways, making sure I didn't forget to eat, sleep, laugh and dance whilst digging into the realms of death and bereavement.

Appendix 1

Protocol/aanvraag ethische comissie. MaNaMa Aselya Tina Nielsen

"The widow effect" is gedefinieerd als de verhoogde morbiditeit en mortaliteit in weduwen in de eerste tijd na het overlijden van de partner. Het is het grootst de eerste 3 maanden maar is ook aangetoond een jaar na het overlijden.

Variaties in de effect zijn onder andere aan de oorzaak van het overlijden van beide partners gerelateerd. Daardoor zijn verschillende mogelijke oorzaken van "the widow effect" aangetoond, die binnen het "bio-psycho-sociale-spirituele" kader van de palliatieve zorg gerangschikt kunnen worden (Christakis and Elwert, 2008). Biologische oorzaken zijn bij voorbeeld de gedeelde levensgewoontes van de partners (rookgedrag, niveau van lichaamsbeweging, dieet etc) (Espinosa and Evans, 2008), en depressie is niet alleen aan het verlies van de levenspartner onafhangelijk gerelateerd, maar ook aan verhoogde mortaliteit en vermindering van sociale waardigheden (Moller et al, 2011).

Scott et al hebben in hun studie "widowhood and spirituality: coping responses to bereavement" beschreven, hoe spirituele coping-strategieën de mogelijke oorzaken van "the widow effect" positief beïnvloeden – mensen die spirituele handvaten in hun rouwproces gebruiken zijn bij voorbeeld minder depressief (Scott et al, 2003). Vanuit een studie over homoseksuele mannen, die hun partner aan aids hebben verloren, bleek het dat spirituele mannen hun CD4-cellen trager daalden dan bij niet-spirituele mannen. Dit suggereert dat spirituele coping ook mogelijks het immuun-stelsel kan beïnvloeden (Bower et al, 1998). Voor mensen die tot een georganiseerde godsdienst behoren, zijn multi-dimensionele coping-strategieën beschreven bij voorbeeld het zoeken van sociale steun binnen de religieuze gemeenschap en/of een spirituele verband met de overledene partner te behouden (door te geloven dat zij elkaar zullen weerzien, dat de partner een soort van beschermengel is geworden etc.) (Scott et al, 2003).

Mensen die gebruik maken van spirituele handvaten om weer mening in hun leven te creëren na het verlies van de partner zijn dus volgens observationele studies minder ziek. Het zou interessant kunnen zijn om te weten, of er onderzoek is gebeurd over spirituele interventies tijdens de eerste rouwperiode. Daarover gaat deze literatuur-studie.

Afhankelijk van het resultaat de bovenstaande literatuuronderzoek, zou ik verder graag:

a) Als er geen bruikbare studies gevonden zijn, zou ik huisartsen in focus-groepen bevragen, of en hoe zij een spirituele interventie zich kunnen inbeelden en mogelijks gebruiken. Hierna een formaat ontwikkelen op basis van een toegepaste "Ars Moriendi" model en die als pilot-project uittesten.
b) Als er al studies met interessante en uitgeteste modellen bestaan, ook, via focus-groepen van huisartsen, een model proberen te ontwikkelen, die aanvaardbaar voor de Vlaamse huisartsen is. Die zou ook als pilot-project uitgetest kunnen worden.

Appendix 2.

Van: Martine Goossens <Martine.Goossens@med.kuleuven.be>
Beantwoorden - Aan: Martine Goossens <Martine.Goossens@med.kuleuven.be>
Datum: vrijdag 29 april 2016 11:04
Aan: Mieke Vermandere <mieke.vermandere@med.kuleuven.be>
CC: Aselya Nielsen <aselya.nielsen@student.kuleuven.be>
Onderwerp: Betreft uw aanvraag Ethische begeleiding masterproeven met titel "Spiritual care after the loss of a spouse" (mp05016)

English version below

Geachte Heer/Mevrouw

De Opleidingspecifieke Ethische Begeleidingscommissie van de opleiding "Master in de huisartsgeneeskunde (Leuven e.a.)" heeft uw voorstel tot Masterproef "Spiritual care after the loss of a spouse" onderzocht en gunstig geadviseerd. Dit betekent dat de commissie van oordeel is dat de studie, zoals beschreven in het protocol, wetenschappelijk relevant en ethisch verantwoord is. Dit gunstig advies van de commissie houdt niet in dat zij de verantwoordelijkheid voor de geplande studie op zich neemt. U blijft hiervoor zelf verantwoordelijk. Indien u van plan bent uw masterproef te publiceren kan deze e-mail dienen als bewijs van goedkeuring.

Dear Mr/Ms

The Supervisory Committee on Medical ethics of the "Master in de huisartsgeneeskunde (Leuven e.a.)" programme has reviewed your master's thesis project proposal "Spiritual care after the loss of a spouse" and advises in its favour. This means that the committee has acknowledged that your project, as described in the protocol, is scientifically relevant and in line with prevailing ethical standards. This favourable advice does not entail the committee's responsibility for the planned project, however. You remain solely responsible. If you intend to publish your master's thesis, this e-mail may be used as proof of the committee's consent.

Met vriendelijke groeten

Opleidingsspecifieke begeleidingscommissie van de opleiding Master in de huisartsgeneeskunde (Leuven e.a.)