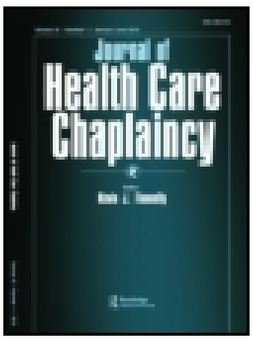

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A spiritual care intervention for chaplains in home-based palliative care: design of a mixed-methods study investigating effects on patients' spiritual wellbeing

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ABSTRACT

Recently, the call for chaplains to become 'research literate' has been recognized by various scholars as well as by practitioners in the field. However, papers that present and discuss the study design and provide guidance on the methodology of chaplaincy research are scarce. The aim of this study is to present the design of a mixed-methods study that investigates the impact of a spiritual care intervention on patients' spiritual wellbeing in palliative, home-based care. It reports on the steps needed to conduct such a study in chaplaincy care, and describes and discusses the study's research design, intervention, participants, sampling strategy, patient and public involvement, procedure, ethical considerations, data collection, and analysis. Presenting and discussing such a design is not only useful for researchers before conducting their study, in order to create transparency, but also for chaplains to improve their knowledge on research methodology and research literacy.

KEYWORDS

Chaplaincy; intervention; methodology; palliative care; study protocol

Introduction

Over the past decades, the call for chaplains to become more involved in research and to become 'research literate' has been recognized by various scholars as well as by practitioners in the field (e.g., Fitchett, 2002; Myers & Roberts, 2014; Snowden et al., 2017; Weaver, Flannelly, & Liu, 2008). This focus on research is needed for the chaplaincy

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profession itself, as a means to gain insight into and improve the practice and care for clients (Fitchett, 2002). Also, it is needed for positioning the chaplaincy profession in relation to other professions, as findings from research may assist in articulating the specific contribution of chaplains (Bay & Ivy, 2006; Fitchett, 2002).

One of the ways to further develop this research-focus is by presenting and discussing study protocols before starting data collection. Study protocols provide a detailed description of the study's rationale and the design and method(s) used. Publishing such protocols is beneficiary to the researchers involved, as it urges them to clearly formulate each step in the research process and to take scientific and ethical issues into consideration before collecting the data. Also, they assist the research community in understanding the design of the study, creating transparency, reducing publication bias, and improving possibilities for other researchers to replicate the study's design (e.g., Chan et al., 2013; Zarin & Keselman, 2007). Moreover, it may contribute to research literacy among practicing chaplains, as it informs them about ways in which to conduct research in chaplaincy care and assist them in critically assessing the research design and chosen methods in order to evaluate the conclusions of research studies.

In other fields of study, such as in medical sciences, reporting study designs is quite common, and guidelines are developed for reporting specific study designs (Schulz, Altman, Moher, & CONSORT Group, 2010; Tong, Sainsbury, & Craig, 2007). However, studies that present the study designs and provide guidance on the methodology of chaplaincy research are scarce. In a recent review of the literature by chaplains and theologians between 2000 and 2018, Poncin, Brandt, Rouiller, Drouin, and Dandarova Robert (2020) identified only seven studies focusing specifically on research methodology, which included one study that presented the study's research design (Bay & Ivy, 2006). Other methodological studies identified by Poncin et al. (2020) focus on using qualitative research methods in chaplaincy research (Fitchett, 2011; Grossoehme, 2014), methodological issues in participatory research (Gilliat-Ray, 2010, 2011; Leshota, 2015), and bias in self-report data (Dodd-Mccue & Tartaglia, 2010). There thus seems to be an urgent need for more studies in chaplaincy research that describe their study designs and methodological considerations.

In the coming decades, an increasing number of people will have to deal with chronic progressive diseases, such as cardiovascular diseases, incurable forms of cancer, chronic obstructive pulmonary disease (COPD), or dementia (World Health Organization, 2018). These disorders have a major impact on a person's quality of life—not only in physical, social and psychological terms, but also in existential or spiritual terms. Although the importance of spirituality in palliative care is widely recognized (Damen & Leget, 2017; World Health Organization, 2002), there is limited research examining the effects of spiritual care interventions for palliative care patients (Gijsberts, Liefbroer, Otten, & Olsman, 2019). Moreover, spiritual care interventions that are tailored to the specific needs of palliative care patients in a secularized and religiously pluralized context, are remarkably scarce (Wierstra, Liefbroer, Post, Tromp, & Körver, forthcoming).

The aim of this paper is to present the design of a study that investigates the impact of a chaplaincy-led intervention to improve the spiritual wellbeing of patients in palliative, home-based care. A six-session spiritual care intervention was designed in which common elements of chaplaincy care are integrated into a new intervention for spiritual care in palliative care. This study protocol presents the research design developed to investigate the

impact of this intervention, and focuses on the main question (MQ): '*What is the impact of the spiritual care intervention on palliative patients' spiritual wellbeing?*' To answer this main question, three research questions (RQs) are formulated:

RQ1: How do patients and chaplains understand spiritual wellbeing?

RQ2: What is the effect of the spiritual care intervention on patients' spiritual wellbeing?

RQ3: In what way does the spiritual care intervention contribute to spiritual wellbeing?

In what follows, a detailed description of the methodological aspects of the design to answer these research questions is provided, including a description of the (a) research design and intervention; (b) participants, sampling strategy, and patient and public involvement; (c) procedure and ethical considerations; (d) data collection; and (e) analysis. The conclusion contains the study's main strengths, limitations and clinical implications.

Method

Design

A combination of quantitative and qualitative methods is used to answer the RQs and MQ. Specifically, to gain knowledge on how patients and chaplains *understand* spiritual wellbeing (RQ1), in-depth, semi-structured interviews are conducted with patients and chaplains after participating in the intervention. Additionally, after each session of the intervention, chaplains will make notes in a reflection-report, in which they report which spiritual aspects were addressed or considered during the session.

Second, to investigate *the effect* of the intervention on patients' spiritual wellbeing (RQ2), survey-responses by participants in the intervention group are compared to two control groups using a multisite trial (Moerbeek, Van Breukelen, & Berger, 2000). Specifically, those participating in the spiritual care intervention (group I) are compared to palliative care patients receiving 'spiritual care as usual' (group II) and palliative care patients on the 'waiting list', receiving no spiritual care (group III). The comparison between the spiritual care intervention (I) on the one hand and the waiting list group (III) on the other will identify overall effects of the developed spiritual care intervention compared to not receiving the intervention. The effects include those factors that are common to several forms of mental care, like the interactions between patient and caregiver, and also those of participants' expectations regarding the received care (see for a discussion on specific, non-specific and placebo-effects Enck and Zipfel (2019)). The comparison between the spiritual care intervention group (I) and the group receiving spiritual care as usual (II) will test the additional effects of the newly developed intervention as compared to the spiritual care as usual. Participants are randomly assigned to one of the three groups, and their responses on three moments in time are compared: at baseline, just before the intervention (T0); after the intervention/10 weeks after baseline (T1); and 20 weeks after baseline (T2) to identify long-term effects of the intervention (Guidi et al., 2018).

Third, to assess *in what way* the spiritual care intervention may contribute to spiritual wellbeing (RQ3), patients make notes after each session of the spiritual care intervention. These are analyzed to collect information on the ingredients they felt contributed (or not) to their spiritual wellbeing and the processes and mechanisms behind this. The findings are triangulated with the information collected during the semi-structured interviews with patients and chaplains and the repeated measures among patients.

Data collected through each of these methods are triangulated to gain knowledge on the overall impact of the spiritual care intervention on palliative patients' spiritual wellbeing (MQ).

Intervention

The aim of the intervention is to improve the spiritual wellbeing of patients in palliative, home-based care, and consists of six weekly, one-hour meetings. The intervention is based on characteristics and practices that are part of spiritual care tools and interventions designed for other populations, and that have been reported in previous studies (e.g., Anbeek, 2017; Ganzevoort, Bernts, Bouwer, Huizing, & Tromp, 2009; Körver, 2013; Kruizinga et al., 2013; Leget, 2017; Olsman, Leget, & Willems, 2015; Post, Verdonck-De Leeuw, Ganzevoort, & Delver, 2015). The characteristics of the intervention include the use of (a) a narrative approach; (b) materiality, ritual and embodied experiences; and (c) imagination and resonance as key elements of existential meaning making. Contrary to most spiritual care practices, this intervention uses these characteristics in a structured manner of six sessions, including exercises and homework assignments for patients. For a full description of the theoretical framework and design of the intervention, see Wierstra et al. (forthcoming).

Participants

The spiritual care intervention is provided by chaplains in the context of the Netherlands. Since recently, spiritual care by chaplains for palliative patients received funding in home-based care settings (Agora, 2019), and chaplains often operate in collective networks for home-based palliative care together with other healthcare professionals. Inclusion criteria for chaplains are: a) a willingness to participate in this study and in the accompanying training for the intervention; b) being registered at the Dutch Quality Register for Chaplains (SKGV); implying that participating chaplains are competent and qualified chaplains; and c) being connected to Networks Palliative Care in The Netherlands (Agora, 2019).

The intervention is developed for patients receiving home-based, palliative care. Inclusion criteria for patients are: a) being diagnosed with a life-limiting disease; and b) willingness to participate in the study, including receiving spiritual care when randomly assigned to group I or II, or receiving no spiritual care when assigned to group III. Exclusion criteria are chosen because they may interfere with participating in the intervention and/or for ethical reasons. These criteria are: a) current psychiatric disorder; b) a life expectancy of less than six months; c) cognitive disability, e.g., a diagnosis of dementia; intellectual disability; d) insufficient proficiency of the Dutch language; and e) not being able to speak or interact for longer than 60 min, even with short breaks; f) aged below 18 years.

Sampling strategy

Patients

The aim is to include approximately 53 patients per group, i.e., I (intervention), II (spiritual care as usual), and III (waiting list). This is an indication of the sample size needed

to identify moderate and large effect sizes (.2/.3 and above). This number is calculated using G*power analysis with repeated measures pre- and post-intervention (effect size=.25; power=.80; alpha=.05). To correct for the multilevel design with several clients per chaplain, the power analysis is checked using PinT: a program for power analysis in two-level designs derived from https://www.stats.ox.ac.uk/~snijders/multilevel.htm (Snijders & Bosker, 1993). This analysis also indicates that this sample size should be sufficient to identify moderate and large effect sizes (effect sizes of .2/.3 and above). Anticipating drop-out rates of around 20% (Bouca-Machado et al., 2017), this implies including $n = 67$ patients in each condition, and $N = 201$ total.

Patients are selected through various centers for palliative care across the Netherlands. These consist of Networks Palliative Care (in Dutch: *Netwerken Palliatieve Zorg*) and Centers for Questions of Meaning in Life (in Dutch: *Centra voor Levensvragen*). Doing so increases the likelihood of including a diverse sample, with respondents from both rural and urban areas and from a variety of religious/spiritual and cultural backgrounds. Only centers with an organizational structure for spiritual care in palliative care are included.

Patient recruitment takes place in close collaboration with these centers. Eligible patients are asked to participate in this study, e.g., by patients' general practitioner, nurse specialist, home care organization, or by the centers upon registration for spiritual care. When patients agree to participate, the researcher sends them a letter containing information about the study, the informed consent form and survey (T0).

Chaplains

Participating chaplains are asked to provide spiritual care as usual to approximately 4 patients, and after completion, they are trained for the intervention and asked to provide the intervention to approximately 4 patients. When aiming for a total of 134 patients to participate ($n = 67$ intervention; $n = 67$ spiritual care as usual; see above), this requires around 17 chaplains to take part in the study. To adjust for potential drop-out on the side of the chaplains, $n = 20$ chaplains will be included.

Chaplains are recruited in collaboration with the centers for palliative care in the Netherlands. When selecting chaplains via these centers, a representative pool of chaplains is aimed for in terms of their religious/spiritual orientation, gender, age, and experience as a spiritual caregiver.

Patient and public involvement

To make sure the intervention is acceptable and feasible for the intended recipients and providers of the intervention, the intervention is designed in collaboration with patients receiving palliative care, chaplains, and scholars. They have provided input and critically assessed the design of the intervention during focus group sessions and expert meetings, and will also be involved during later stages and implementation of the study's findings. Also, an online pilot-training (due to Covid-19) has taken place to teach chaplains in how to use the intervention. Results of the study will be disseminated to the public through relevant websites, information leaflets among stakeholders, and scholarly publications. After refinement based on the results of this study, the intervention will be

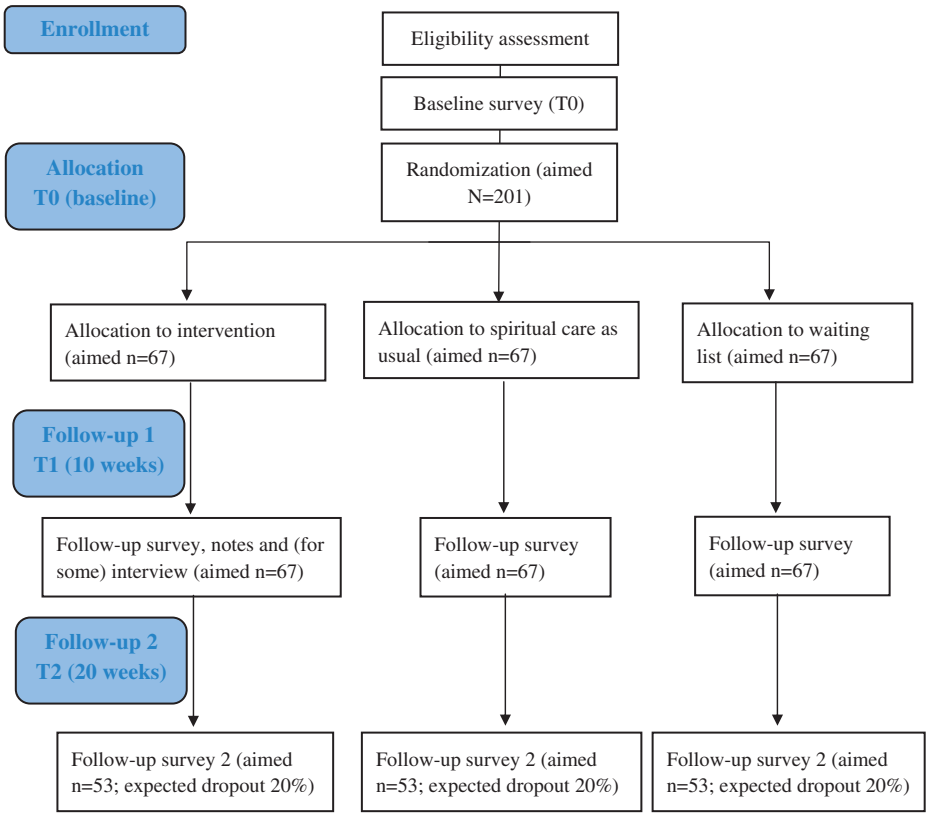

Figure 1. Flow diagram of procedure for patient enrollment and data collection.

implemented via centers of palliative care in the Netherlands and through educational programs for chaplains.

Procedure

For an overview of the procedure for patients, see Figure 1. Once chaplains and patients are selected for participating in this study (see above) the following steps are taken. First, chaplains receive a letter containing the informed consent form and are requested to fill this out and return through mail. Then chaplains are requested to provide spiritual care as usual to approximately 4 patients and to fill out a survey (see below). After completion, they are trained for the intervention and asked to provide the intervention to approximately 4 patients.

Second, each patient who is interested in participating in the study receives a letter containing information about the study, the informed consent form and survey (see below; T0) and is requested to fill these out and return through mail. The survey is filled out before randomization, because knowing that one will be participating in an intervention (or not) may create bias in the way in which one responds to the survey. After returning the informed consent form and survey, patients are randomly assigned, using SPSS randomization, to one of the groups. The researcher informs patients by telephone to which group they are assigned. For those participating in either the

intervention (I) or spiritual care as usual (II) group, the chaplain subsequently calls them by telephone to arrange a meeting. Patients participating in the intervention group receive instructions for the sessions by the chaplain.

Third, both patients and chaplains participating in the intervention group are asked to make notes on their experiences with the intervention (see below). They are asked to send their notes to the researchers after the final session of the intervention. The notes are used for research purposes and returned afterwards.

Fourth, after approximately 10 weeks, all patients receive survey T1 and are requested to fill this out and return the survey. Also, several chaplains and patients participating in group I are asked to be interviewed by one of the researchers. In addition, chaplains in group II are requested to fill out a survey regarding the characteristics of the spiritual care they provided. For a good comparison, ideally participants in the intervention (I) group receive survey T1 after finishing the intervention after the same time span since T0 as do other participants. To make sure all participants in group I have finished the intervention at T1, we chose approximately 10 weeks after T0 as a timeframe. Although the intervention itself takes six weeks to complete, we anticipate that there will be a few weeks between T0 (baseline) and the actual start of the intervention (two to three weeks), and we anticipate approximately one additional week in case one of the intervention meetings would have to be postponed.

Finally, approximately 20 weeks after baseline (T0), all patients receive survey T2 and are requested to fill this out and return the survey.

Ethical considerations

To make sure ethical aspects are considered for this research project, the research proposal is examined and approved by the ethical review board of Tilburg School of Catholic Theology, Tilburg University (identification code: ERB-TST # 2020/6). In addition, the research ethics committee of Brabant (identification code: NW2020-05) confirmed that this study does not fall within the scope of the Dutch law on medical-scientific research involving human subjects. All participants in the study are required to sign an informed consent form before participating. This form includes information about voluntariness and respondents' rights, costs and benefits of participating in this study, and confidentiality of the data.

Voluntariness

Participants have the right to withdraw from the study at any moment during the research process. Furthermore, to make sure that participants assigned to the waiting list are not involuntarily detained from spiritual care, they are offered the possibility to receive spiritual care upon request. Although doing so may lead to noncompliance for some respondents in this control group, following the "intention-to-treat" principle ("once randomized, always analyzed") they remain in the study regardless of what happens after randomization has occurred, except for their own withdrawal (Kruse et al., 2002).

Costs and benefits

Participating in this study requires both chaplains and patients to put effort and spend quite some time in this project. Specifically, for chaplains, participation requires them to be trained in a new intervention, to provide spiritual care as usual and spiritual care following the intervention to patients, to fill out a survey, make notes, and to be interviewed. For patients, participation in this study requires them—if assigned to group I or II—to receive spiritual care, and to fill out a survey (10 to 20 min) at three moments in time. Furthermore, those assigned to the intervention group are asked to keep track of a reflection report with short questions after each session, and—for some of these patients—to be interviewed once about their experiences. Although research in palliative care suggests that palliative care patients generally do not find it difficult to refuse participation (Ling, Rees, & Hardy, 2000), to be sure that participation will not get burdensome for patients, participating chaplains are instructed/trained to be aware of such signals and to offer the possibility to postpone or withdraw from the study.

Although this is quite an effort to put into research, there are several benefits for participants as well. Chaplains and patients contribute to a better understanding of spiritual wellbeing and to the development of spiritual care for palliative patients. In addition to this benefit for research, participating in research can be a positive experience for patients, for instance as it may foster their feelings of autonomy (Fairhall et al., 2012; Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis, 2006). Also, for those who are assigned to group I or II, spiritual care is supposed to contribute to their spiritual wellbeing. For participating chaplains, learning to apply a new intervention in their spiritual care provision is a huge benefit. They may therefore also receive accreditation points for participating in the study.

Confidentiality of data

To make sure that data is collected and analyzed in a confidential manner, a data management plan is written and examined by the ethics committee. Written data, like surveys and reflection reports, will be transcribed and after that, deposited in a safe place for confidential material. The interviews are audiotaped and transcribed verbatim and anonymously. The audio records will be kept until the end of the study, and the transcripts will be kept for 10 years. All data will be coded and kept as a safe file, which is only accessible for the researchers via a password. In another file, under another password, the researchers will keep the file that connects the codes with the participants. Doing so will assure that participants' data is managed in a confidential manner. Following the FAIR principles (Wilkinson et al., 2016), after finishing the study some of the—anonymized—data may be reused for future research purposes.

Data collection

Interviews among patients and chaplains

To collect information on patients' and chaplains' understanding of spiritual wellbeing (RQ1) in-depth, semi-structured interviews are conducted with patients and chaplains

after participating in the intervention. The number of respondents to be interviewed depends on the number needed to achieve data saturation. First, 10 patients and 10 chaplains are interviewed and their transcripts analyzed. Then another 5 patients and 5 chaplains are interviewed and their transcripts analyzed. If this raises new data concerning RQ1, the sample is extended by conducting and analyzing interviews with 5 more patients and/or chaplains. The same procedure is repeated up to a maximum of 25 patients and 20 chaplains—a maximum that was chosen for reasons of feasibility.

The interviews include questions about patients' and chaplains' understanding of spiritual wellbeing, such as 'What aspects in life do you value most?' and 'When do you experience life as meaningful?'. An interview guide is used to structure the interviews, and topics include themes that relate to central aspects of the intervention (see Wierstra et al., forthcoming), such as relationship with self and others, perception of meaning and a meaningful existence, hope and despair. Also, patients' and chaplains' experiences of the intervention in relation to patients' spiritual wellbeing is addressed during the interviews.

Survey among patients

To test the effectiveness of the intervention (I) in comparison with the control groups (II and III) (RQ2), all patients participating in each of the groups are requested to fill out a survey at three moments in time. The variables included in this survey are described below.

Primary and secondary outcome variables. The primary outcome variable is spiritual wellbeing, and is measured in three ways. First, it is measured by the Dutch validated and translated version of the EORTC QLQ SWB32, which includes the dimensions (a) 'relationship with self'; (b) 'relationships with others'; (c) 'relationship with someone or something greater'; (d) 'existential'; and (e) (if applicable) 'relationship with God'. These dimensions relate to theoretical assumptions underlying the spiritual care interventions, in which the intervention is meant to increase patients' relationship with self (a), others and/or God (b + c + e), and their sense of meaning and coherence in the world (d). The questionnaire consists of 32 items and the scales' reliability is good (Cronbach's alpha ranging from .68 to .84; Vivat et al., 2013, 2017).

Second, the Northwestern Ego-integrity Scale (NEIS; Dutch version by Kleijn et al. (2016)) is used to measure ego-integrity and despair. This questionnaire relates to Erikson's (1950) phase of ego-integrity versus despair, which forms one of the theoretical fundaments of the intervention and which is addressed in the fifth and final sessions of the intervention. The subscales contain 4 and 5 items respectively (9 items in total). The scale's reliability is sufficient (Cronbach's alpha .72 and .61) and previous research found positive improvements on this questionnaire in relation to a narrative intervention (Post, Delver, Verdonck-De Leeuw, & Ganzevoort, 2016).

Third, spiritual wellbeing is assessed using five items of the Dutch *Utrecht Symptoom Dagboek 4 D* (USD-4D) that are intended to measure palliative care patients' overall spiritual wellbeing in a different way than the first and second measure, including a stronger focus on how patients view their current life, their relationships with others, and the end of life (Vries, 2019).

Since having a disease in the palliative phase may give rise to heightened feelings of anxiety and depression (Velosa, Caldeira, & Capelas, 2017; Wilson et al., 2007), anxiety and depression are included as secondary outcome variables and measured using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith (1983), translated by Pouwer, Snoek, & Van der Ploeg). This scale consists of 14 items measuring depression (7 items) and anxiety (7 items), with sufficient reliability (Cronbach's alpha HADS-D varies from .67 to .90; Cronbach's alpha HADS-A varies from .68 to .93; Bjelland, Dahl, Haug, & Neckelmann (2002)).

Independent variables. The three groups—group I (intervention), group II (spiritual care as usual) and group III (waiting list)—form the independent variables and are being compared with each other at three moments in time.

Other variables. The following variables are included for descriptive purposes: patients' demographic data (gender, age, marital status, level of education, religious affiliation), medical history, physical wellbeing (eight items derived from Körver (2013) and based on the EORTC QLQ-LC13), use of other health care, and being interviewed after T1 (registered by the researcher).

Survey among chaplains

All chaplains are asked to fill out a survey after finishing spiritual care as usual. To be able to interpret results of group I with group II, a number of key aspects of spiritual care as usual are charted. These include questions about the frequency and duration of the encounters, themes that have been discussed, methods, assignments and materials used, goals pursued by the chaplain, and the way in which the accompaniment is terminated. In addition, information on the following descriptive variables is collected: demographic data (gender and age), religious affiliation, authorization and/or ordination, and years of experience as a chaplain.

Reflections by patients and chaplains

To collect information on the way in which the intervention contributed to patients' spiritual wellbeing (RQ3), patients make notes during the intervention in their workbooks, in which they reflect on the meetings and the topics discussed herein. Furthermore, to investigate how spiritual wellbeing is understood by chaplains (RQ1), chaplains participating in the intervention make notes in a reflection-report. These reports contain notes on what spiritual aspects were—according to the chaplain—addressed or considered during the sessions. These reports also contain questions about the extent to which chaplains followed the intervention protocol, to assess chaplains' fidelity to the intervention.

Analysis

Qualitative data are transcribed, and inductively and thematically analyzed using Atlas.ti. Quantitative data are analyzed using statistical software like SPSS and/or MlWin

(Charlton, Rasbash, Browne, Healy, & Cameron, 2020). This dataset will be hierarchically organized, with for each chaplain observations per client at several moments in time. Linear Mixed Models (LMM) are used to test differences in repeated measures (over time) between the three groups (intervention, spiritual care as usual, waiting list), including clustering within chaplains of the first two groups as a random effect.

Conclusion

In this paper, the design of a study that investigates the impact of a chaplaincy-led intervention to improve the spiritual wellbeing of patients in palliative, home-based care was presented. The description of the study's rationale and methods provide transparency about the way in which this study is intended to be conducted. A main strength is that the presented design uses mixed methods, which assists in gaining insight into the impact of and the experience with the spiritual care intervention.

Home-based care is a relatively new field for chaplains in the Netherlands. The success of this study in part depends on the number of patients and chaplains that can be included for this study. Therefore, efforts are made to develop a referral structure in close collaboration with urban and peripheral centers for palliative care in the Netherlands. By connecting with these centers, the aim is to include the number of respondents needed for this study, and to make the results generalizable to the national context. If the intervention turns out to be successful, future studies could investigate its impact in other countries as well.

The findings of this study may improve chaplains' palliative, home-based care, as it provides them with insights into the impact of and processes behind the intervention. Also, findings on the impact of the intervention may assist chaplains in engaging with other professionals (Bay & Ivy, 2006; Kestenbaum et al., 2015). We hope that the presentation of this study design will inspire other researchers to also share their study designs on chaplaincy care.

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