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Recruiting participants to a randomized controlled trial testing an intervention in palliative cancer care – the perspectives of health care professionals

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Introduction

Randomized controlled trials (RCTs) are deemed the most reliable way to infer a causal relationship between an intervention and outcomes. The key feature of the RCT is prospective, random allocation of participants to an intervention and control arm (Polit and Beck, 2012). A challenging context for RCTs is the context of palliative cancer care, which uses an approach focused on promoting symptom relief and quality of life for patients with life-threatening illness and their families (WHO, 2017). It has been considered especially difficult in matters concerning identifying and recruiting participants which could impede the initiation and completion of trials (Grande and Todd, 2000). Sample sizes are often smaller than anticipated, even though significant time and resources are devoted to participant recruitment (Kutner et al., 2010). Health care professionals are usually the ones responsible for recruiting eligible participants to trials in palliative cancer care and may hence have a great influence on the success rate (Kars et al., 2016). RCTs could be regarded with skepticism by health care professionals as the potential benefits for participants could be questionable. Conducting trials in palliative care settings could also be questioned due to the vulnerability of patients and family caregivers (Holm et al., 2015, Kars et al., 2016), even though they often report positive attitudes to participate in research (Aoun et al., 2017).

An important area of palliative cancer care is supporting family caregivers (i.e. friends, relatives or partners) who often provide various forms of extensive care to the patient (Morris et al., 2015). This often constitutes a great burden which can lead to an increased risk of mental and physical ill-health (Williams and McCorkle, 2011). Despite the obvious need for support, there are few interventions targeting family caregivers in palliative care and even fewer have been robustly tested (Kamal and Dionne-Odom, 2016). In general, interventions aiming to support family caregivers in palliative cancer care could be described as complex interventions which means that the intervention involves more than one component and unlike drug trials, the active ingredient could be hard to specify (Campbell et al., 2000). A recent review found 14 interventions directed at supporting family caregivers between 2004 and 2014, but, of these, only 7 were RCTs and recruitment problems were common, which led to insufficient study power (Chi et al., 2016).

It has been suggested that for complex interventions, quantitative outcome measures should be completed with qualitative evaluations of intervention processes (Campbell et al., 2000). To avoid recruitment problems and selection bias in future studies, it would be valuable to analyze the experiences of health care professionals when recruiting participants to an RCT in the context of palliative cancer care. Therefore, the aim of this study is to describe how health care professionals experienced recruiting participants to an RCT testing an intervention for family caregivers in specialized palliative cancer care.

Methods

This study has a qualitative approach with an explorative design. Ethics approval was obtained from a regional ethical review board (No. 2012/4:3, 2012/377-31/4).

Study context: a complex intervention

Data were collected from a psycho-educational group intervention trial for family caregivers at 10 palliative home-care settings in a metropolitan area in Sweden. The trial was orchestrated by the authors of this study, who were all part of the same research group. Health care professionals (nurses, physicians and social workers) at the palliative care settings were responsible both for recruiting participants to the trial and for delivering the intervention. One or two registered nurses at each setting had been selected by the head nurse to be mainly in charge of the recruitment process. The trial protocol was developed in accordance with the CONSORT-statement and has been registered at <https://www.clinicaltrials.gov> (ID: NCT02482415).

The trial was an RCT where family caregivers could be randomized to the intervention or to standard support. Before commencement of the trial, health care professionals from the 10 palliative home care settings were invited to a one-day workshop where the intervention content was covered and they were introduced to the recruitment process of an RCT. Health care professionals were instructed to recruit both patients and family caregivers to the trial. For convenient reasons, the recruitment would usually take place when the health care professionals made visits to provide care in the patients' homes. The inclusion criteria for patients were: being in receipt of palliative care, and having a limited life expectancy that

was nevertheless longer than five weeks. Patients were not included in active data collection, but were asked to give their consent and nominate family caregivers to the trial. Thus, the recruitment process included two steps; recruiting patients, and then recruiting family caregivers. Family caregivers who were not living in the same home as the patient were contacted on telephone, or the patient was asked to pass on the invitation. If the patient accepted, the family caregiver(s), received written study information and were asked to complete a baseline questionnaire. This was sent to the authors, who randomized the family caregiver to either the intervention group or control group. The control group received standard support from the palliative care teams. The family caregivers received a letter informing them which group they had been allocated to and family caregivers who had been placed in the intervention group also received an invitation to the sessions.

The main purpose of the psycho-educational intervention was to increase family caregivers' feelings of preparedness for caregiving. The intervention was delivered in group format and included a structured program, focusing on the informational, practical and emotional needs of family caregivers. It has been thoroughly described in a previous article (removed for blinded review). During the intervention sessions, the health care professionals presented topics such as palliative care and symptom management, practical nursing care and emotional grief reactions. The intervention also included discussions and reflections between family caregivers.

In total, 270 family caregivers were recruited to the trial and 40 health care professionals were involved in the recruitment process. Every setting delivered the intervention 1-4 times.

Data collection

To evaluate the experiences of recruiting participants to a trial in palliative care, focus group discussions were held with health care professionals who had been involved in the recruitment process. To capture a deeper understanding of the experiences, interviews were also held with nurses who had been mainly responsible for the recruitment.

In total, 5 focus group discussions were carried out and 25 health care professionals (16 nurses, 4 physicians and 5 social workers) agreed to participate on two occasions within a period of 6 months, to capture experiences both from the early phase of recruitment and later. Two authors moderated each focus group with the use of an interview guide focusing on the experiences of recruiting participants. Examples of questions from the interview guide included “What strategies did you adapt when you recruited patients and family caregivers to the trial?” and “Which problems did you encounter in the process of recruitment?”

Within 5 months after trial completion, 9 interviews were performed by two authors of this study (removed for blinded review) with 11 registered nurses, one man and 10 women, from 8 settings to further explore the aim of this study. For practical reasons, the interviews were carried out in different formats. One nurse was interviewed twice because there was not enough time to cover the interview on the first occasion, three interviews were carried out pairwise with nurses who had worked together with the recruitment, and the remaining four were individual interviews. The nurses had worked in palliative care from between 3 and 18 years. Most had specialist education degrees mainly in palliative care and oncology. A small number had earlier experience of participating in research. An interview guide was used with

questions such as: “How did you experience being responsible for the recruitment of participants to the RCT?”

Analysis

The results from the interviews and focus group discussions were transcribed and data were analyzed using interpretive descriptive methodology (Thorne, 2016), which provides a meaningful approach to describe human experiences and allows for a deeper understanding of the phenomenon, in this case to recruit participants to an RCT in palliative cancer care.

Inductive analytic techniques were used to extract thematic representations of commonalities and diversities within the health care professionals’ accounts of their experiences. Unlike other qualitative methodologies, interpretive description does not advocate that the researcher should bracket his or her preconceptions, but rather use it as a lens to view data through. After reading the interviews, the material was coded broadly. These codes were used for exploration of patterns and for alternative interpretations within the dataset. Data were independently analyzed by three of the authors throughout the process. Codes, patterns and interpretations were frequently discussed between all the authors during the analysis to validate and attain agreement on the findings. Four themes illustrating health care professionals’ experiences of recruiting participants to the RCT were formed.

Results

Learning to communicate the RCT design to patients and family caregivers

Experiences from the early phases of the project revealed that health care professionals considered the RCT-design, with allocation to one of two arms, something that was difficult

to explain when recruiting patients and family caregivers. Initially, they struggled to verbalize the difference between inviting family members to a group intervention or a research trial. Because the recruitment process took two steps where the patient's consent was first required, the health care professionals experienced it as even more complicated. The health care professionals felt that it was difficult to make the information clear and precise because they could not inform the participants which group they would be allocated to. In several cases, health care professionals experienced misunderstandings as family caregivers reacted with surprise when they were allocated to one of the two groups.

I think this has been a great problem because when I called to invite those who had been allocated to the intervention, several people did not understand that they had been put there. They thought they were just supposed to answer the questionnaires. So, I think it's important to make it more distinct (Nurse 8, focus group session 1).

The health care professionals found that informing patients and family caregivers about the RCT-design was a process of learning where they gradually discovered strategies and simplified routines to improve recruitment. Hence, by the later phases, they had found more effective ways to approach the participants.

My experience is that we changed tactics before the second round, when we were recruiting. We enhanced the fact that you accept to be part of a research trial. Then it's a game of chance if you end up in one group or the other. Just to make that clear (Physician 1, focus group session 2).

Because the process of recruiting to the RCT was challenging, the health care professionals found it necessary to initiate regular contact with the authors of this study to gather support. They reported that they often made calls, e-mailed questions and initiated discussions and that reflections about the best ways of communicating the RCT-design took place.

Being influenced by preconditions in the palliative home care setting

The health care professionals believed that the context of palliative home care had an impact on the recruitment of patients and family caregivers. Their patients were cared for in their homes all over the region and the frequency of visits from health care professionals could vary greatly, from daily to monthly. Additionally, family caregivers were not always living with the patient and thus, were not present when health care professionals visited. This was experienced as challenges, both in being able to inform them about the study, and delivering invitations and questionnaires. The health care professionals often found it necessary to let the patient pass on the invitation to the family caregivers. They also found it difficult to follow-up when patients and/or family caregivers had been informed about the study and wanted time to consider whether they wanted to participate.

It has been tough to distribute the invitations and an enormous job to call everyone and follow-up on the phone. I couldn't always get in touch with them (the family caregivers), sometimes I was met with the answering machine so there were a lot of phone calls (Nurse 7, individual interview).

The health care professionals experienced that recruiting to the RCT demanded much of effort and commitment from them to perform the practical administration and inform about

the trial. They sometimes found it difficult to find space within their everyday work. Some health care professionals were given extra time by their employers for recruitment, but, due to limited resources at the settings, this could not be granted to everyone. The health care professionals said that they tried to involve colleagues and find routines to approach patients and family caregivers during their visits. This could mean that they were present at work every morning to remind colleagues about the invitations, placing the invitation in each of the patient's records or making notes in the digital records system. The health care professionals felt that dedication and interest was needed in the recruitment of patients and family caregivers, something that could not always be guaranteed when so many health care professionals were involved.

And that's been our constant dilemma, to give out the invitations. So, I still feel...that those (health care professionals) who just hand them (the invitations) over, here you have this envelope, then it has turned into nothing (Nurse 2, individual interview).

The health care professionals stated that the recruitment to the RCT was influenced by the generally short time the cancer patients spent in palliative home care. The patients often had uncertain prognoses and their survival time was short. Because the home care settings also accepted patients who were not in a palliative stage of illness, health care professionals found that it could be troublesome to identify eligible participants.

Facing dilemmas related to inclusion criteria

During recruitment, health care professionals realized that patients and family caregivers were not always fully aware of the patient's condition and sometimes they had not fully

acknowledged the concept of palliative care. Health care professionals frequently discussed the inclusion criteria, which stipulated that the patient should be in palliative care with a limited survival time. They had to consider that the intervention content was tailored to fit family caregivers of patients in palliative care and therefore, they found it necessary to be careful in the process of recruitment so as to not cause distress to the patient or the family caregiver.

I have asked my colleagues to be a little bit sensitive about this, so they (patients and family caregivers) won't be completely shocked. There was this patient who was coded category Z (in the medical record), which means he is palliative, but it wasn't pronounced that he had acknowledged it himself. Sometimes, there can be a palliative code even though they believe something completely different. You need to be careful with that (Nurse 3, focus group session 1).

The fact that the patient's consent was required before the family caregiver could be recruited was something that the health care professionals reflected on. Most of the time they would have preferred to proceed directly to the family caregivers, but they considered it fair and important to be open with the patient. However, the health care professionals felt that many patients wanted to protect their family caregivers who they believed were already under a lot of stress. Health care professionals sometimes found it difficult to accept that the patient declined participation and that the family caregiver was never given a chance to reflect on whether they wanted to participate in the RCT. The health care professionals contemplated how much energy they should devote to the matter.

It almost became a little bit unethical to push them (the patients) too many times and sometimes it didn't really make me feel right, they have this situation and then we go, "Have you done this?" or "Have you sent this to your daughter?" Sometimes I could have pushed them but I choose not to because it just didn't feel right in that situation (Nurse 2, focus group session 1).

Experiencing conflicts between randomization and the approach to offer best possible support

A general experience presented by the health care professionals was that recruiting patients and family caregivers to a study with an RCT design was a breach of their professional ambition to always offer the best possible support. They emphasized that patients and family caregivers were in a difficult phase and that family caregivers were often under a lot of pressure. The health care professionals believed in the benefits of the intervention and felt uncomfortable recruiting them to a study where it was not guaranteed that they would be offered to take part. Health care professionals experienced that certain family caregivers were in more need of support than others and found it conflicting when they were allocated to the control group. Additionally, they were confronted with feelings of disappointment from family caregivers.

We have had many disappointed family caregivers who have cried on the phone because they have not been randomized to the intervention (Nurse 6, individual interview).

In other cases, health care professionals experienced the opposite reaction; family caregivers who were happy to take part in research and complete questionnaires, but who felt that they

had no need to take part in the intervention. Health care professionals witnessed that sometimes, family caregivers could not spare the time to take part in the intervention because they were occupied with caring for the patient's needs.

Discussion

The experiences of the health care professionals involved in the RCT reveal that recruiting participants from the palliative cancer care settings involved many complex challenges, aligning with conclusions in earlier research studies (Kars et al., 2016). In this study, a major problem seems to have been to correctly inform participants about the RCT design and to avoid misunderstandings. Taking the time to give adequate information has been highlighted as important (Hanson et al., 2014), however, perhaps more emphasis should be placed on how patients and family caregivers make sense of what participation would mean rather than on providing the information (Ohlen et al., 2016). The design of this RCT, where both the patient and the family caregiver had to be approached, seems to have created additional challenges to the recruitment process. It was more time-consuming and added to the difficulties of informing about the trial because it had to be repeated twice. To promote recruitment to RCTs, a phased model has been suggested, which involves a careful explanation of study procedures, addressing uncertainties and showing confidence (Realpe et al., 2016). It has also been suggested that potential barriers should be identified early and addressed through feedback (Paramasivan et al., 2015). The health care professionals in this study regarded the recruitment as a process of learning, which indicates that they might have been in need of training to improve their skills in communicating key RCT concepts before the recruitment was initiated to make them feel more confident (Townsend et al., 2015).

A further problem that health care professionals faced was that the recruitment process demanded more time than was anticipated. This required help from their colleagues, something that was not always guaranteed. Teamwork could be integral to successful recruitment to RCTs, especially when the intervention involves various professional groups (Strong et al., 2016). Communication with the authors of this study was also deemed helpful by the health care professionals in their recruitment. Earlier research have advocated that collaborative relationships between health care professionals and researchers could be vital in the recruitment process (Campbell et al., 2016). Hence, it could be important to focus both on enabling teamwork between health care professionals and collaboration between health care professionals and researchers.

A review of the literature has found that family caregivers often act as gatekeepers in studies directed at patients in palliative care. They are often motivated by a fear of burdening the patient (Kars et al., 2016). In this study, a reverse phenomenon was observed, where patients were eager to protect their family caregivers who they believed were already in a stressful situation. However, health care professionals in the study still felt that it was right to ask for the patient's consent. To minimize gatekeeping, it has been suggested that patients and family caregivers should be approached and informed about a trial at the same time (LeBlanc et al., 2013). This strategy could have facilitated the health care professionals' recruitment, but would have been difficult to arrange in this trial because patients and family caregivers were not always living together.

Although patients in this trial had been diagnosed as being in a palliative stage of their illness, the results indicate that they and their family caregivers might be struggling to make

sense of what receiving palliative cancer care actually means (Ohlen et al., 2013). The health care professionals' experiences reveal that they found it necessary to be cautious when they approached participants to avoid distress. The words "palliative care" can be very emotionally laden and there may be a link in people's minds between palliative care and dying (McIlfatrick et al., 2013, McIlfatrick et al., 2014). Earlier results have noted that recruitment in palliative care could require greater investments of time and effort than non-palliative care trials (Hanson et al., 2014). This is very much in agreement with the results of this study, where the recruitment process demanded much more time than had been assigned. However, it is also possible that with more knowledge and training, the process would have been smoother for the health care professionals. When conducting sensitive research with vulnerable participants it could be important to spend extra time and effort preparing for the recruitment process (Kavanaugh et al., 2006). A pilot study could also have been used to identify factors likely to influence recruitment (Hubbard et al., 2015).

It has previously been noted that health care professionals may feel uncomfortable about the RCT-design (Kars et al, 2016) and, in this study, health care professionals found that the design was contrary to their approach to give the best possible support, especially when family caregivers in need of support were not allocated to the intervention. By offering both the intervention and the control group some kind of additional support, the feelings of disappointment in both health care professionals and family caregivers could have been avoided. Although the RCT-design is considered the "gold standard" in intervention effectiveness, the experiences of the health care professionals open up a discussion to advocate the use of a non-randomized trial design, such as quasi-experimental. This design includes a pre- and post-intervention test and may or may not also include a control group

(Costantini, 2007). It has been argued that a pre-test/post-test trial with a control group in palliative care could make recruitment numbers higher and might avoid problems with attritions associated with disappointment. Such a design would explore the preferences of family caregivers and therefore include those who would otherwise have declined to participate and, thus, would make the results more generalizable (Schildmann and Higginson, 2011). A limitation is that this may lead to selection-bias (Costantini, 2007), but the strengths of this design are still worth considering.

Methodological considerations

Throughout the study procedure, there has been a constant strive for rigor. In qualitative studies, the dependability of the results could be influenced by the authors' skills and abilities (Patton, 2002). In this case, the authors have recognized expertise in conducting qualitative research and significant experience in palliative cancer care, which could have influenced their interpretation of data. However, according to the interpretive descriptive approach, the authors' preconceptions should not be bracketed, but rather be used in the process of analysis (Thorne, 2016).

Data was collected both through repeated focus group discussions and interviews, which is considered something that could increase the confirmability of the results. The credibility of the study is illustrated through descriptions of the analytic process (Thorne, 2016). Frequent discussions concerning the interviews and the analysis were held between the authors to discern alternative interpretations and reach agreement to validate the findings. The transferability of the study is illustrated in thorough descriptions of the research settings and

the complexities of the intervention. Quotes were carefully chosen to demonstrate data that support the findings (Houghton et al., 2013).

This study does not claim to communicate all the relevant information about recruitment to an RCT in palliative cancer care. In the interpretive descriptive approach, it is acknowledged that no matter how many participants included or interviews performed there will always be new data that may represent new conditions and knowledge and thus saturation cannot be assumed (Thorne, 2016). However, it could be argued that this study was based on rich, experiential data, something that contributes to the trustworthiness of the study.

Conclusions

This study contributes to a deeper understanding of the challenges involved in conducting an RCT in the context of palliative cancer care. There seems to be a core conflict between the approach in palliative care to offer the best possible support and the RCT-design itself. One of the pillars of palliative care is supporting family caregivers based on their individual needs, while in this research design, a randomization process decides who is allocated to the intervention group and who to the control group, resulting in conflicting feelings for health care professionals when recruiting to such trials. A further challenge in recruitment is the rapid development of treatments in palliative care, which makes it more difficult to estimate the time of survival. To facilitate recruitment under these circumstances, health care professionals may need training to improve their communication skills, but it could also be necessary to consider alternative research designs than RCTs in palliative cancer care interventions.

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