Abstract: Considered to be one of the essential dimensions of Palliative Care (PC), spirituality has undergone rigorous scientific research in the United States and Europe. In Brazil, the implementation of PC services and the discussion on the integration of spirituality in this context are relatively recent. This study presents the current state of the art on this subject. Searches were carried out in the CAPES Journals Portal, Virtual Health Library, SciELO and PUBMED. Twenty-five studies were selected for analysis, and 17 had a central focus on spirituality in PC. The literature evidences a growing understanding about the role of spirituality in this context; the need for theoretically founded research and of practical models of spiritual care; lack of professional training in relation to the subject and lack of knowledge about the importance of specialized spiritual assistance. For the advancement of knowledge in this field, future studies should consider these gaps and potentialities.

Keywords: Palliative care. Spirituality. Health. Spiritual care.

Resumo: Considerada uma dimensão essencial dos Cuidados Paliativos (CP), a espiritualidade tem sido objeto de rigorosa investigação científica nos Estados Unidos e Europa. No Brasil, a implementação de serviços de CP e a discussão sobre a integração da espiritualidade neste contexto são recentes. Este estudo apresenta o atual estado da arte sobre o tema. Foram realizadas buscas no Portal de Periódicos CAPES, Biblioteca Virtual em Saúde, SciELO e PUBMED. Ao todo, 25 estudos foram selecionados para análise, sendo 17 com foco central sobre espiritualidade nos CP. A literatura evidencia percepção crescente acerca do papel da espiritualidade nesse contexto; necessidade de pesquisas teoricamente fundadas e de modelos práticos de cuidado espiritual; carência na formação profissional em relação ao tema e desconhecimento sobre a importância da assistência espiritual especializada. Para o avanço do conhecimento nesse campo, futuros estudos devem considerar tais lacunas e potencialidades.

Introduction

In 2018, the Brazilian government published, in the Official Gazette, the Resolution No. 41 of 31 October 2018 (Brasil, 2018) on guidelines for the organization of Palliative Care (PC), in the field of public health. This fact emerges as a watershed in health care policies in Brazil.

Comprised of 9 articles, the Resolution establishes, in Article 1, Sole Paragraph, that “palliative care should be part of the integrated continuing care offered within the scope of RAS [Rede de Atenção à Saúde / Health Care Network]” (Brasil, 2018, p. 276). The document follows the 2002 definition proposed by the World Health Organization (WHO), explaining that “palliative care is an approach that improves the quality of life of patients and their families who are facing the problem associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification, and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Brasil, 2018, p. 276).

Eight objectives and thirteen principles that should guide the organization of PC are listed (Articles 3 and 4) in the Resolution. Two of these principles refer to spiritual issues, highlighting the need for “integration of psychological and spiritual aspects in patient care”, and the promotion of “relief of spiritual and existential suffering of patients and their families” (Brasil, 2018, p. 276).

On the one hand, the publication of this document emerges as a promise of a “revolution” in health policies and in the provision of PC services in Brazil, on the other hand, it does not guarantee a substantial change in the PC scenario in the country, neither in the short nor in the medium term, since for real changes, a significant contingent of trained personnel will be needed. The last survey of the National Academy of Palliative Care (ANCP), from August 2018, reports that up to that date, the total number of registered services was of 177 (ANCP, 2018). Obviously, this is a small number for a country with approximately 210 million inhabitants (IBGE, 2018, online) with a large contingent of people enduring less healthy social conditions, therefore more vulnerable to severe diseases, and with a significant increase in the elderly population (above 60 years old) reaching the baseline of 30.2 million (14.54%) of the total population in 2017 (IBGE, 2018, online). In 2012, the percentage of older people was of 7.4% (IBGE, 2018, online).

In the WHO categorization on the development of PC in the world, Brazil was classified as level 3a (WPCA; WHO, 2014). This group comprises countries with isolated provision of palliative care,

the development of palliative care activism that is patchy in scope and not well supported; sourcing of funding that is often heavily donor-dependent; limited availability of morphine; and a small number of hospice-palliative care services that are often home-based in nature and relatively limited to the size of the population (WPCA; WHO, 2014, p. 37).
There are 74 countries that comprise the group 3a, including Colombia, Paraguay, Bolivia, Guatemala, Angola, Mozambique and Congo (WPCA; WHO, 2014, p. 37).

Facing the current reality, and the movement that is beginning in terms of expanding the organization of PC service, a question arises about a theme that is at the base of the philosophy of PC – i.e., the integration of the spiritual dimension as an expression of comprehensive care. In this sense, there is no way to conceive a PC service unrelated to spiritual care, its “fundamental component” (Puchalski et al., 2014, p. 642), or as stated by Leget (2018, p. 2), “providing spiritual care is an intrinsic part of providing good palliative care”.

In view of this, questions arise such as: Is spirituality a dimension effectively integrated in PC? How is it integrated (or can be integrated) into the care practice? Is it possible to identify spiritual needs to be met? Who should do that? Are there specialized professionals in this area? Is spiritual care a “specialty” within PC services or is it something to be accomplished by the entire team? This study aims to present a mapping of S/R in palliative care in Brazil based on the literature produced in the country, indicating the current state, possible trends, and some of the main challenges and/or opportunities related to its effective integration in the practices of care. In times of implementation of PC within primary healthcare, reflection on this topic is quite timely.

Method

This study is an integrative literature review. Based on the results of studies already performed, this method aims to synthesize the knowledge built around a specific question on a given topic. It has as its final purpose both the incorporation of the applicability of important research outcomes (Souza; Silva; and Carvalho, 2010, p. 102) and the identification of existing gaps as well as the definition of future research agenda (Kastner et al., 2012, p. 114). In this sense, the guiding question of this study was: “What have the empirical studies on spirituality/religiosity, in the context of palliative care in Brazil, shown?” Studies published in Portuguese and English, conducted in Brazil, and with no limitation of the period of time, were collected. The search terms used in Portuguese and English, as well as the total of studies captured in each database are described in Table 1.

In addition to the key terms extracted from the guiding question, two other searches were conducted, including the terms “psychology” and “chaplaincy”, or “chaplains”. This choice was made in order to capture as much studies as possible on S/R and Palliative Care, and also to analyze how these two fields deal with the dimension of spirituality in the specific context of Palliative Care in Brazil.

The search in the databases was carried out in November and December 2018, in the CAPES Journals Portal (Coordination for the Improvement of Higher Education Personnel); Virtual Health Library (VHL); SciELO (Scientific Electronic Library Online); DLTD (Digital Library of Theses and Dissertations) and PUBMED. The selection of studies was done through a careful analysis process as described in Figure 1.
Table 1 – Search terms used in databases.

<table>
<thead>
<tr>
<th>Search Terms</th>
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<th>SciELO</th>
<th>PUBMED</th>
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<td>62</td>
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</table>

Source: Authors’ own (2019).

Consistent with the proposed objective, the selection of studies for analysis took into account the following criteria for inclusion: 1) to have been developed in Brazil; 2) to have been published in Portuguese and/or English; 3) to address S/R in the specific context of Palliative Care - in other words, studies with an approach on spirituality with patients undergoing cancer treatment without explicit reference to the context of Palliative Care were not included; 4) to present results on S/R in PC even though S/R has not been the focus of research; 5) to have access to the full text. Following studies were excluded: 1) theoretical essays; 2) studies in the context of chronic diseases (or potentially PC, such as cancer, heart and kidney disease), but without a direct reference to Palliative Care; 3) duplicate studies, with Portuguese and English versions (only one version was selected), or another version of the same study, based on the same sample.

Results

The search in the databases resulted in 637 studies, including articles, theses and dissertations. Table 2 and 3 present the search terms used and the number of studies
Figure 1 – Flow diagram of studies selection process.

Source: Authors’ own (2019).
found in each database. After the first evaluation of the captured studies, applying the inclusion criteria, 115 were selected for analysis. A second evaluation was conducted with the participation of one other reviewer. The application of the criteria on the studies selected for analysis resulted in the final inclusion of 25 studies, 17 of them with a central focus on Spirituality/Religiosity in Palliative Care (Table 2 and 3).

Field of Knowledge and geographic location in which the studies were developed, language used in the publications and studies approach

Nursing is the area with the highest number of studies, including six articles, one thesis and three dissertations. Eight of them with a central focus on S/R. Medicine comes next and is the one with the most published articles, five of them in in English. Psychology occupies the third position in number of studies with five studies (four published).

Regarding the geographical origin, studies on S/R in Palliative Care have been restricted to seven Units of the Federation. São Paulo is the State with the highest number of studies (seven) focused on S/R.

In relation to the language used in the publications, eight were published only in Portuguese, five in English and four had a bilingual publication in Portuguese and English. That is, 52.9% of the total of published articles are available in English. The qualitative approach was predominant and was used in 76% of the studies (n = 19). Five studies (20%) favored a quantitative methodology and only one used the mixed method of approach.

Table 2 – Studies on Spirituality/Religiosity in Palliative Care.

<table>
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<th>Thesis</th>
<th>Location of Studies</th>
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<td><strong>3</strong></td>
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</tbody>
</table>

Source: Author’s own (2019).
Table 3 – Studies on Spirituality/Religiosity in palliative care with central focus on S/R

<table>
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<th>Field</th>
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<th>Thesis</th>
<th>Location of studies</th>
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</tbody>
</table>

Total          | 11       | 4             | 2      | 17                  |

Source: Author’s own (2019).

Evolution of Scientific Production and the notion of S/R

The search was done without a predetermined limitation in years of publication and captured two articles published before 2010. The first one in 2003 (Elias, 2003) and the second one in 2006 (Elias et al., 2007). Of the 25 analyzed studies, 17 (13 articles, 3 dissertations, 1 thesis), or 68%, were produced between 2014 and 2018. In relation to the total number of 17 scientific publications, 11 of them had S/R as the central focus (72.7%), and 8 of them were published from 2015 on (Figure 2).

Figure 2 – Evolution of scientific publication

Source: Author’s own (2019).
Topics covered

The selected 25 studies can be classified into three broad categories: 1) Role of S/R in PC; 2) Modes of integrating S/R in PC by health professionals; 3) S/R as a “finding” in the investigation of other PC topics.

Role of S/R in the context of PC: source of meaning making and spiritual/religious coping resource for patients and families

Eight studies investigated the role of S/R for patients and families in the context of PC. For patients, S/R helps discovering meaning in experiences of suffering, contributes to better coping with death, provides hope, support (Benites, Neme & Santos, 2017), comfort and strengthening (Medeiros & Marroquim, 2012), and better quality of life (Camargos et al., 2015; Matos et al., 2017). Quality of life was linked to meanings of health, well-being, happiness and spirituality, and allowed the authors to affirm that spiritual/religious coping strategies should be encouraged to patients in palliative care (Matos et al., 2017).

Researchers also found that 90% of advanced cancer patients report spiritual struggles and seek spirituality in ways that deal with these feelings (Camargos et al., 2015). However, “these spiritual needs are often supported minimally or not at all by the medical system, potentially influencing the spiritual QOL in a negative way” (Camargos et al., 2015, p. 13). The authors also observed that “patients exhibited higher spiritual QOL scores compared with health professionals” (Camargos et al., 2015, p. 13).

Spirituality was studied as a spiritual resource as well as a spiritual/religious coping strategy regarding prayer activity (Paiva, Carlos et al., 2013). Researchers investigated 221 outpatients with advanced cancer, in Palliative Care. The authors observed that higher religion scores were associated with lower levels of inflammation in advanced cancer patients still undergoing Anti-neoplastic Therapies. Additionally, “higher Individual Prayer Activity was an independent good prognostic factor in patients on active ANTs”, and “global religion scores were associated with quality of life, symptoms, inflammatory markers, and survival” (Paiva, Carlos et al., 2013, p. 1).

Spirituality is a source of meaning making and coping also for families of PC patients (Paiva, Bianca et al., 2015; Miqueletto et al., 2017; Rocha, 2017). Spirituality/Religiosity is not only a coping resource in dealing with the disease of the family member, but also a means to spiritual development, life re-signification, and strengthening and support (Paiva, Bianca et al., 2015). However, researchers also observed (Miqueletto et al., 2017) that despite the fact that S/R contributes to the meaning construction of life experiences, families do not find space to express these issues with health professionals. The authors point out that these families “recognize S/R as a strengthening element when facing difficulties caused by illness, but they strongly depend on the availability of the team to increase their experience” (Miqueletto et al., 2017, p. 1616). Spirituality benefits the health of the entire family facing the adversity of this context and in this sense, nurses not only should provide spiritual care to family members, but they also should receive adequate academic training (Rocha, 2017).
Modes of integrating S/R in PC by health professionals: Practical Application and Education

Nine studies presented results on modes of integrating S/R in PC from different approaches and perspectives: the multi-professional team (Arrieira et al., 2018; Ferreira et al., 2015), nurses (Evangelista et al., 2016), and residents of medicine (Zaccara, 2014). Arrieira and others (2018) pointed out that the multi-professional team reported that spiritual care was carried out through prayer, the offer of comfort, support in the search for meaning of the experience of suffering both for patients and for the multi-professional team itself.

The lack of training for spiritual care provision was highlighted in the research among nurses (Evangelista et al., 2016) and residents of medicine (Zaccara, 2014). They also admit having difficulties in identifying the patient’s spiritual needs and feeling insecure about how to deal with these issues as they emerge. Resende (2014) defends the application of Acupuncture to minimize “spiritual pain” (or “total pain”), understanding the use of this technic as a way to provide spiritual care.

Three distinct proposals for the practice of spiritual care were developed by Elias (2003), Araújo (2011), and Dezorzi (2016). The pioneering study in this context was of the psychologist Ana Catarina Elias (2003); that together with other colleagues (2006; 2007) developed an intervention technique called RIME: Relaxation, Mental Imagery, and Spirituality to deal with the spiritual pain of patients - children, adolescents and adults, and families of PC patients.

By means of action-research, Araujo (2011) developed a care model based on his practice as a nurse in his doctoral study. The spiritual care was delivered to adult patients and was based on human-to-human relationship (nurse-patient), and meaning-making in suffering.

The nurse Luciana Dezorzi (2016) developed a proposal of training professionals for the practice of spiritual care in PC. The Spirituality Education Module was developed for health professionals involved in Palliative Care (but not restricted to this group) and it was published as an e-booklet (Dezorzi, Raymundo & Goldim, 2016). The author affirms that there were positive educational intervention results, “indicating that the use of an education module can collaborate to minimize the gaps left during the training process” (Dezorzi, 2016, p. 65).

S/R as a “finding” in the investigation of other PC topics

Although the subject of spirituality was not the main focus of research in eight studies, it emerged as a “finding”. In those studies, researchers were interested in demonstrating: 1) the nurses’ performance with the child in PC (Monteiro et al., 2014); 2) the death and dying process of end-of-life cancer patients (Tomaszewski et al., 2017); 3) the experience of family caregivers in PC (Lima & Machado, 2018); (Rezende et al., 2010); 4) communication (Geovanini, 2011) and the perception of several elements involved in the end-of-life experience of patients in palliative care (Carvalho et al., 2019; Castro and Barreto, 2015;
Marinho, 2010). The results showed that nurses are concerned with offering spiritual, emotional and religious support to children in PC (Monteiro et al., 2014); that spirituality is a source of meaning-making (Tomaszewski et al., 2017), a coping resource (Lima & Machado, 2018), and a source of greater well-being (Rezende et al., 2010) for PC patients and their relatives. The studies also show that the physician’s own spirituality influences on how communication is performed (Geovanini, 2011), as well as on their perception of spiritual suffering (Castro & Barreto, 2015). Health professionals have difficulties to recognize and meet the patients’ spiritual needs (Marinho, 2010). Carvalho et al. (2019, p. 1) observe that “less than 15% of patients received attention for their spiritual needs and/or received psychological support”, and, according to Marinho (2010, p. 129), there is no evaluation of spiritual suffering by the team, and the dimension of spirituality is misunderstood as religiosity and, therefore, considered of a “private nature” (Marinho, 2010, p. 131).

Discussion

Is there consensus in Brazilian Research about the use and meaning of the term spirituality?

Among the 17 studies that focused on the investigation of S/R in PC, 14 (82.3%) presented a definition for spirituality. Brazilian researchers seem to follow the international trend of a concept of spirituality that emphasizes the dimension of meaning and purpose of life, quoting the well-known American researchers of the Spirituality and Health field, directly or indirectly, such as the researchers Koenig; McCullough and Larson (2001); the psychologist of Religion, Park (2013); the doctor of internal medicine, Puchalski (2014); and others. Most Brazilian researchers differentiate spirituality and religiosity, as evidenced in 70.5% (n=12) of the studies. This differentiation begins to appear explicitly from 2010 on. The two studies prior to 2010 presented a definition of spirituality with greater emphasis on intrapersonal and transcendental connection.

Is there consensus on the meaning of “spiritual care” as well as a protocol or recommendations on how it can be integrated by multidisciplinary PC teams?

Although the term “spiritual care” was mentioned in 64.7% (n=11) of the 17 studies that had S/R in PC as its central focus, only three studies presented a definition: the dissertation of Resende (2014), and the doctoral theses of Araújo (2011) and Dezorzi (2016). The term appears as “synonymous to transpersonal care” (Resende, 2014, p. 11 [footnote]), as “essentially relational” (Araújo, 2011, p. 128), but with “its central focus on the search and discovery of the meaning of life, in order to have full realization and to end despair” (Araújo, 2011, p. 128), and as the care “that recognizes and responds to the needs of the human spirit, especially when confronted with traumas, health problems or sadness” (Dezorzi, 2016, p. 31). Dezorzi points out that it “begins with encouraging human contact and a compassionate relationship, able to move in the direction that the need requires” (2016, p. 31-32).
In articles with a central focus on palliative care published in nationally recognized journals, the term initially appeared in the study published in 2015 (Ferreira et al., 2015). Apart from the context of palliative care, the term appears for the first time, in a nationally recognized journal, in 2009, as shown in the study on interdisciplinary spiritual care, published by Hefti and Esperandio (2016). Therefore, it can be observed that in the scenario of PC in Brazil, the notion of spiritual care is not only very recent, but also its theoretical reflection is still incipient. This reality only highlights the biomedical emphasis of professional training (Marinho, 2010), leading therefore to a reductionist understanding of spirituality, since they only consider its form of “religious expression”. This posture brings difficulty in identifying, understanding and dealing with the strong role of S/R beliefs in PC. However, in these cases, professionals argue that religiosity is a matter of intimate forum, so the health professional does not have the right to address such issues (Esperandio & Machado, 2018; Marinho, 2010).

None of the studies discussed the issue of protocol on spiritual care, nor did they make practical recommendations other than the emphasized statement about the need for training for a practice that addresses the spiritual needs of patients in PC and their family members.

Who is responsible for spiritual care in Palliative Care?

The question of responsibility was not discussed in any of the papers. There isn’t also any mention of a chaplain, or “spiritual caregiver”, or another term referring to the person who performs the function of specialist in spiritual assistance. It is also noteworthy to mention that, in Brazil, there was found no study on chaplaincy in the context of palliative care. Searches on “chaplaincy and palliative care”, or “spiritual care and palliative care” did not result in including any studies. The published studies on hospital chaplaincy were not developed in the PC scenario.

Although several studies mention the term “spiritual care”, there is not enough clarity of its meaning and application. It may be one of the reasons for explaining why the studies do not address whether spiritual care is something to be practiced by the entire PC team, how it should be done, or if it would be the prerogative of some specialty.

There is a consensus in the international literature (Puchalski et al. 2014; Leget, 2018), that spiritual care, as dealing with the spiritual needs of patients and their families, is essentially interdisciplinary. In this sense, a screening of such needs can be performed by any professional of the team (Puchalski et al. 2014; Hefti & Esperandio, 2016). However, it is the responsibility of the spiritual caregiver to further assess the spiritual needs (whether of patients or their family) and attend to cases that require their expertise as such. The competent work of a specialized spiritual assistant in the palliative care team is a great contribution. For instance, in decision-making situations in which spiritual/religious beliefs predominate, patients demonstrate confidence and openness for the discussion of treatment options with the specialized spiritual assistant. Health professionals acknowledge the strength of religious beliefs in health decision-making, for example, in palliative sedation (Eich et al., 2018 ), or in invasive treatments (Elliot et al., 2012; Maessen et al., 2009; Johnson et al., 2016).
In Brazil, although religion plays a central role in the lives of the majority of the population, as Huber & Huber (2012) and Esperandio and others (2019) have shown, hospitals, in general, do not have the tradition of having a chaplain, with few exceptions. Chaplaincy in Brazil works in a voluntary and fragmented way; with little interreligious dialogue in the hospital context (Gentil; Guia; Sanna, 2011), and with insufficient training for performing spiritual care in PC. In this scenario the participation of a spiritual caregiver in the multidisciplinary team is rare. In occasional and specific situations, the spiritual leader of the patient and family is called.

*Is empirical research on S/R in PC theoretically anchored?*

The implementation of Palliative Care services in Brazil, as well as the studies on S/R in this context are only in their beginning, but in straight growth. The increase in the volume of research and the implementation of PC in Brazil seem to be moving in parallel as both started to gain more visibility in the years between 2015 and 2018.

If on the one hand this increase still does not demonstrate significant deepening or advance in theoretical knowledge on the subject, on the other hand, the interest and necessity of research becomes evident. In several studies, there seems to be a concern to prove the relationship (generally positive) between spirituality and health outcomes, highlighting therefore, the relevance of integrating spirituality in this context. But there is a lack of proposition, application and evaluation of models of spiritual care. Debates of national consensus, as it occurred in the United States and Europe on the meaning of spirituality and the practice of spiritual care by multi-professional teams, are necessary in Brazil.

Few empirical studies present a theoretical framework to support the collection and analysis of data. Theory is, therefore, a gap to be filled in future studies, especially considering the rapid expansion of PC services and the need for such services to be theoretically well based, including spiritual care as one of its essential components (Puchalski et al. 2014; Nolan; Saltmarsh; Leget, 2011)

**Conclusion**

In summary, studies show that the investigation on S/R in the context of PC is recent, growing from 2015 on, emerging in parallel with the progression in the provision of palliative care services. This seems to indicate that Brazil has great potential for the development of studies on spiritual care in palliative care. There is a consensus among researchers on the notion of spirituality as being broader and distinct from religiosity, referring to issues of meaning and purpose, but a national consensus definition of spirituality and spiritual care is needed. Such a consensus might contribute both to the advancement of theoretical-practical knowledge in the field of care ethics and to guide the organization (and implementation) of spiritual care as a specialized service integrated to the multidisciplinary team in Palliative Care.

Spiritual care itself has been little investigated, its notion is unclear, the few available models have not yet been sufficiently tested, there is no available and specific protocol
or training on practice in PC, and it is dependent on the willingness, intuition and the spirituality of the health professional. However, many health professionals, mainly in the area of nursing, value spiritual care and seek to integrate it into the practice of care, even though intuitively and without any training.

It is concluded that, although spirituality is generally a foundational dimension in the constitution of human subjectivity (that often, in its religious expression, occupies a central position), it has not been fully and properly integrated into the Palliative Care services in Brazil. The manifestation of its aspects, whether in the form of a positive resource or a need to be met, is often ignored, minimized, devalued and/or unidentified by healthcare professionals. The multidisciplinary team has, in general, diverse difficulties when dealing with the content of this dimension.

Consequently, there is a lack of professional training, a lack of propositions on spiritual care protocols and models, and a lack of theoretically based empirical studies, that deepen the issues of S/R in the context of PC. There is also a lack of studies on spiritual care for patients, family members and multidisciplinary team as well as regarding the way S/R impacts in decision-making in health and in the process of coping with a serious and life-threatening disease. Given this, it can be said that this area of knowledge has great potential to be developed and the number of researchers interested in fostering this field is significant.

Finally, due to the databases used and the established inclusion/exclusion criteria, some studies may not have been captured in this survey, thus presenting a possible limitation of the study.

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