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CONCEPTUALIZATION OF THE CENTERED CARE IN OLDER PEOPLE: ORIGINS AND PATHS

CONCEPTUALIZAÇÃO DOS CUIDADOS CENTRADOS NA PESSOA IDOSA: ORIGENS E RUMOS

CONCEPTUALIZACIÓN DE LA ATENCIÓN CENTRADA EN LA PERSONA MAYOR: ORÍGENES Y DIRECCIONES

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ABSTRACT

Introduction: Regarding centered care in older people it is intended to: explore the origins, influences and conceptual evolution; describe the development path and current trends and reflect on potential future developments.

Methodology: From the research conducted in English, Spanish and Portuguese, in the databases EBSCO-PSY/ASC, PubMed, SciELO and B-on, 39 documents were included.

Results: The perspective of person-centered attention had its genesis in humanistic psychology that inspired the application of the approach in several areas. Kitwood developed person-centered dementia care in response to traditional biomedical focused models. These developments were revolutionary and motivated the progress that is presented throughout the article.

The evolution of elderly centered care has been diverse and constant. Although there is no universal definition, the relevance dedicated to the study of the values, elements and domains that guide philosophy is highlighted. Currently, this paradigm is considered as the highest quality standard in terms of care for older people, regardless of their diagnoses.

Conclusion: Advances in this field show concern for ethical attention and respect for people's well-being and rights. Thus, this approach has many potentialities with consequences in terms of scientific study, conceptual development, policy definition and planning, execution and evaluation of practices in gerontological services.

Keywords: Aged; Aged Rights; Client-Centered Care; Gerontology; Health Services for the Aged; Patient-Centered Care.

RESUMO

Objetivos: Em relação aos cuidados centrados na pessoa idosa pretende-se: explorar as origens, influências e evolução conceptual; descrever o percurso de desenvolvimento e tendências atuais bem como refletir sobre potencialidades futuras.

Metodologia: Da pesquisa efetuada em inglês, espanhol e português, nas bases de dados EBSCO-PSY/ASC, PubMed, SciELO e B-on, incluíram-se 39 documentos.

Resultados: A perspetiva da atenção centrada na pessoa teve a sua génese na psicologia humanista que inspirou a aplicação da abordagem em diversas áreas. Kitwood desenvolveu os cuidados centrados na pessoa com demência em resposta aos modelos tradicionais com foco biomédico. Estes trabalhos foram revolucionários e motivaram progressos que são apresentados ao longo do artigo. A evolução dos cuidados centrados na pessoa idosa

tem sido variada e constante. Ainda que não exista uma definição universal, salienta-se a relevância dedicada ao estudo dos valores, elementos e domínios orientadores da filosofia. Atualmente, este paradigma configura o mais alto padrão de qualidade ao nível dos cuidados a pessoas mais velhas, independentemente dos seus diagnósticos.

Conclusão: Os avanços neste campo demonstram investimento na atenção ética, no respeito pelo bem-estar e direitos das pessoas. Esta abordagem possui inúmeras potencialidades de operacionalização com consequências ao nível do estudo científico, do desenvolvimento conceptual, da definição de políticas e da planificação, execução e avaliação de práticas nos serviços gerontológicos.

Palavras-chave: Assistência Centrada no Paciente; Direitos dos Idosos; Gerontologia; Instituição de Longa Permanência para Idosos; Pessoas Idosas.

RESUMEN

Introducción: En relación con la Atención Centrada en la Persona Mayor se pretende: explorar los orígenes, las influencias y la evolución conceptual; describir la ruta y las tendencias actuales y reflexionar sobre posibles desarrollos futuros.

Métodos: De la busca realizada en inglés, español y portugués, en las bases de datos EBSCO-PSY/ASC, PubMed, SciELO y B-on, se incluyeron 39 documentos.

Resultados: La perspectiva de la atención centrada en la persona tuvo su origen en la psicología humanista que inspiró la aplicación del enfoque en varias áreas. Kitwood desarrolló la atención centrada en la persona con demencia en respuesta a modelos tradicionales con un enfoque biomédico. Estos trabajos fueron revolucionarios y motivaron progresos que se presentan a lo largo del artículo.

La evolución de la atención centrada en los ancianos ha sido variada y constante. Aunque no existe una definición universal, se destaca la relevancia dedicada al estudio de los valores, elementos y dominios que guían la filosofía. Actualmente, este paradigma establece el estándar de calidad más alto en términos de atención para las personas mayores, independientemente de sus diagnósticos.

Conclusión: Los avances en este campo muestran preocupación por la atención ética y respeto por el bienestar y los derechos de las personas. Por lo tanto, este enfoque tiene numerosas potencialidades con consecuencias en términos de estudio científico, desarrollo conceptual, definición de políticas y planificación, ejecución y evaluación de prácticas en servicios gerontológicos.

Descriptores: Atención Dirigida al Paciente; Derechos de los Ancianos; Gerontología; Hogares para Ancianos; Personas Mayores.

INTRODUCTION

Population aging is an achievement that generates different challenges and needs, such as increasing dependency situations that require professional care services[1-3]. The assistance-based models that have dominated the provision of care to older people[4-5], tend to focus on disease/deficits and services, have a rigid organization, standardized practices and standardized procedures[6]. This type of model has shown signs of low sustainability in the respect for the rights of older people and in the promotion of quality care[3-4]. In this context, several entities, and authors (e.g., Martínez, 2016 and World Health Organization, 2015), defend the need to change models, making them increasingly centered on the person.

The initial perspective of person-centered care had its genesis in humanistic psychology, especially in client-centered psychotherapy by Carl Rogers[7-9]. This current advocated that each person was a unique, multidimensional and developing being. Regarding integral well-being, it recommended that the psychosocial, relational and spiritual dimensions were as important as the physical ones[10]. Consequently, a change was made in traditional therapeutic relationships (characterized by distancing and focusing on difficulties and procedures), towards interactions with an emphasis on close therapeutic relationships, centered on the person, individual experience and recognition of abilities[11]. In this sense, Rogers argued that a person-centered approach should foster the optimization of human potential[12], and that the professional should promote three basic conditions: unconditional acceptance, empathy and authenticity[9]. Subsequently, the intervention should be non-directive, with the therapist's role to respect and promote the person's self-actualization tendency (i.e., the natural propensity for evolution in a positive direction in the search for self-realization and improvement)[9]. It was also argued that, with increasing age, human capacities/needs for growth and development remained relevant. Thus, in order to facilitate evolution, in the advanced stages of life, opportunities for continuous learning, personal challenges and enjoyable close relationships should be provided[12].

This perspective inspired the application of the person-centered approach in several areas and services such as education, health and gerontology[1,7-9,13]. Along these lines, in the 80s, Bradford Dementia Group's founding gerontologist, Tom Kitwood, encouraged the contextualization of this approach in providing care to people with dementia[14-15]. In the late 90s, the concept of Person Centered Care on People with Dementia (PCCPwD)[16] spread, especially in the United Kingdom[7], and was introduced in institutional contexts[17]. This paradigm has become generalized in the care of older people regardless of their diagnoses[18].

This article aims to: 1. Explore the origins, influences and conceptual evolution of Person Centered Care on Older People (PCCOP); 2. Describe the development path of this approach and its current trends; and, 3. Reflect on its future potential. For this, the narrative synthesis of the results will be presented according to two main themes contained in the articles explored: origins of the PCCOP and influential conceptual frameworks.

METHODOLOGY

In line with the aforementioned objectives, the methodology of narrative literature review was adopted because it consists of an appropriate review to describe, explore and discuss the state of the art and development of a subject from a theoretical or contextual point of view[19-21]. Although this type of review does not require systematic and exhaustive analyzes[19-21], it has sought to provide greater objectivity and systematicity by planning and achieving an organized and comprehensive research methodology.

Initially, the terms associated with the theme were explored through the identification of keywords in relevant articles, as well as linguistic variants and semantic networks (in English, Spanish and Portuguese). For this purpose, dictionaries of synonyms and idioms and thesaurus MeSH and DeCS were used. The terms contained in a greater number of documents (in the databases: EBSCO-PSY/ASC, PubMed, SciELO and B-on) were combined and related to Boolean operators.

This was followed by the application of research equations (e.g., ("person centered care" OR "patient centered care") AND (senior* OR elderly* OR gerontolog*)), in the aforementioned databases and languages, without temporal criteria. The exploration and application of the research strategy took place between March and July 4th of 2019.

Through the databases, 1671 records and 62 cross-references were identified. Afterwards, the articles were extracted, organized in Mendeley and all duplicates were eliminated. Then, the selection phase was carried out by title and abstract and, later, by full text (figure 1). It were included articles of review, opinion, empirical research, reports and academic papers that addressed pertinent information about the origin and path of the PCCOP, as well as milestones of their development. Study protocols were excluded. Subsequently, the results were extracted and organized chronologically in pilot tables and the narrative synthesis of the information was performed.

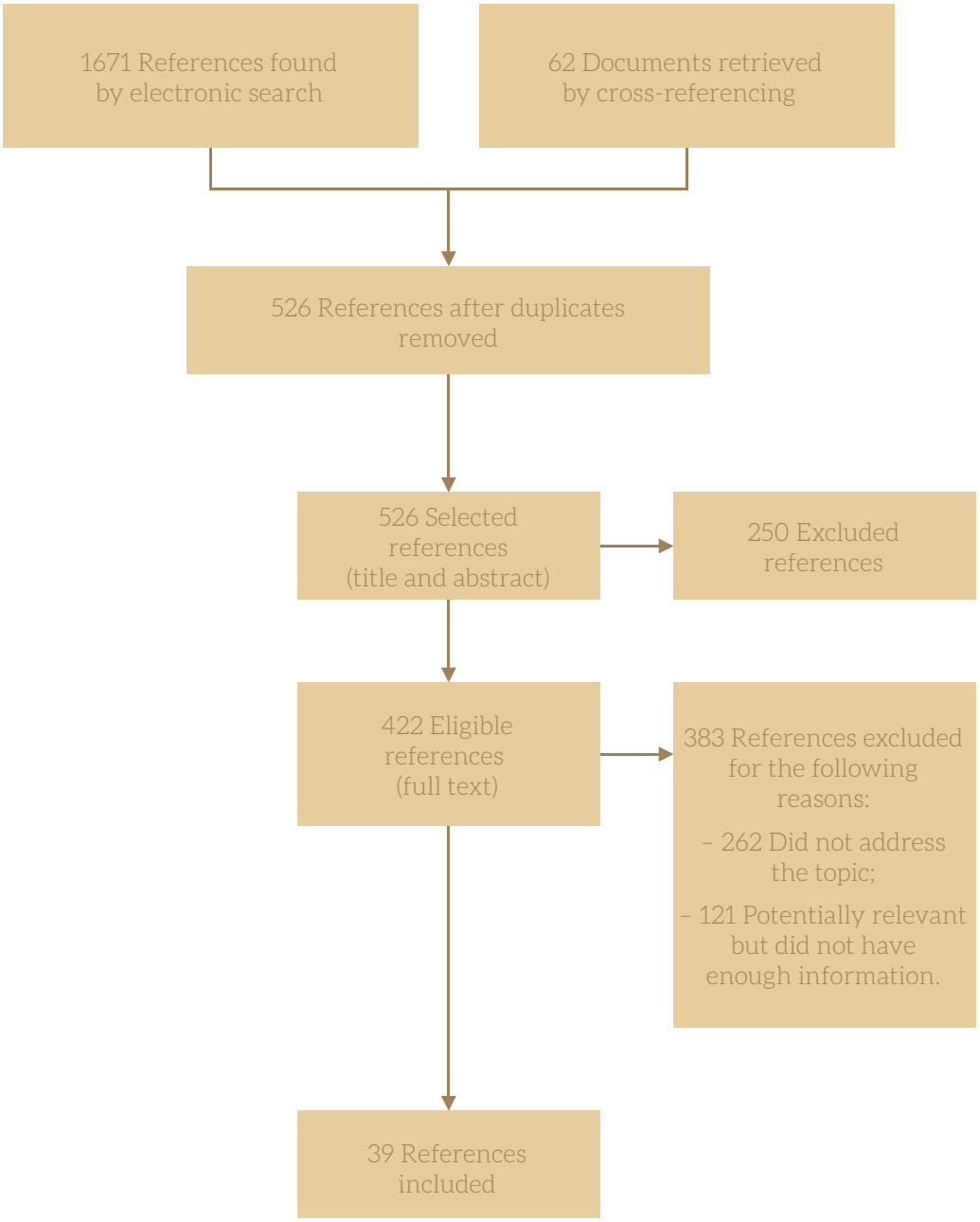

Figure 1 – Diagram of the selection process.

RESULTS

The 39 documents were distributed as follows: 15 review/opinion articles; 4 systematic literature reviews; 16 empirical investigations; 2 reports; and, 2 doctoral theses. The documents were organized according to the themes they presented: 21 addressed the origins of the PCCOP and 8 explored other influential conceptual frameworks. Additionally, 10 articles contained both domains simultaneously. Therefore, an organizational structure for the synthesis of results was adopted, congruent with the aforementioned subtopics.

PCCOP Origins

Perspectives on dementia – disease-focused models versus person-centered approaches

The PCCPwD emerged as a response to criticism of the model designated by some authors as biomedical[11,13,22]. This traditional curative model, in addition to promoting the supremacy of the professional considering him/her a specialist in relation to the person's life[23], considered aging as pathological and interpreted the person as a passive care receiver[4]. In this sense, dementia was understood as a condition in which deterioration and difficulties were inevitable and the center of attention. Thus, it was considered that people with dementia would have little potential, that the lack of quality of life was inevitable and nothing could be done to help them live well[22,24]. Subsequently, rigid, standardized treatment focused on procedures was promoted[25-26].

In contrast, authors Kitwood and Bredin[25] presented evidence that suggested that dementia did not progress universally in a linear manner, varying idiosyncratically. In this vein, they understood that the difficulties that people with dementia experienced were not just a consequence of the disease itself. In other words, cognitive and behavioral symptoms were the expression of multiple causes[11,27]. They concluded, therefore, that the environment and relationships could have a more significant effect than the disease itself[8,11,27].

In this context, there was a reconceptualization of dementia and its symptoms as a process determined not only by pathological aspects, but as the result of a dynamic interaction between neurological impairment and psychosocial factors[11]. Consequently, Kitwood defended the need to create a new culture of care, in which the person should be the focus and practices should be guided by high quality[22,28-29]. To achieve this, a set of constructs and values were implemented in order to expand the potential for interpretation and intervention in supporting people during their life experiences with dementia[22,25].

"Personhood", psychosocial needs and PCCPwD

In Kitwood's perspective, a PCCPwD approach should preserve and protect "personhood" and address the person's needs throughout the course and development of dementia[22,30].

The concept of "personhood" refers to the attributes and status of "being a person"[31], designating the condition that is granted to human beings[32-33]. This construct: expresses the values and uniqueness of each individual[8,34-37]; it has a holistic character[8,36-37] and identifies the importance of links and interconnection[8,35,37].

Furthermore, Kitwood identified (in addition to physical needs), five psychosocial needs that should be considered in care[11,25,31]: 1. love and comfort, 2. attachment; 3. inclusion; 4. occupation in interests; 5. integral identity and recognized by others. The author considered that these needs are present in all human beings, however, they are likely to be exacerbated in people with dementia because they are less likely to take measures to satisfy them[25,31]. Consequently, the PCCPwD approach interpreted non-adaptive behaviors as signs of unmet needs[38]. This means, it recognized that if there were unmet needs, these could trigger behavioral or neuropsychiatric symptoms[39]. Based on this premise, it was recommended that caregivers be more attentive, offering an answer to the individual's needs instead of focusing on behavioral control[39].

It should be noted that the concept of "personhood" and the response to individual needs are central lines in the approach of PCCPwD[11,13,27]. In this context, Kitwood maintained that the use of the term PCCPwD brought together ideas and ways of working[11]. In other words, the PCCPwD did not represent any specific therapeutic technique or intervention, but they configured a multidimensional approach to care, that is, a philosophy consisting of a set of fundamental values[8,40].

Consequences for the practice of the PCCPwD approach

In PCCPwD, the criteria for well-being and quality of life are subjective, idiosyncratic[12,16] and inherent to the promotion of "personhood"[31]. In this sense, it is important to be aware of the interactions that influence these variables, both in the positive and negative directions[31].

It was in this line that Kitwood developed, in 1997, the "Positive Person Work" (PPW) and the "Malignant Social Psychology" (MSP):

- MSP brings together behaviors that threaten the individuality and well-being of the person with dementia (cheating, not empowering, infantilizing, intimidating, labeling, stigmatizing, overcoming/not giving due attention, non-validating, rejecting, objectifying, ignoring, imposing, depriving, accusing, interrupting, enjoying and devaluing). In Kitwood's perspective, this type of depersonalizing tendencies may occur not due to malicious intentions, but as a product of the lack of valuation and specialized training of caregivers[11,31,40-41].

- PPW defines a set of behaviors that can occur during interactions in the provision of care and tend to promote humanization and well-being of the person even in the face of the decline in their cognitive abilities[31]. These attitudes are part of: 1. recognizing and accepting the person, life story, thoughts, feelings and desires; 2. negotiate your preferences with the person and involve them in decisions; 3. establish a collaborative partnership relationship; 4. recreate through meaningful and enjoyable activities; 5. receive/accept the person's kindness; 6. promote stimulation of the senses ("timalation"); 7. celebrate the person's achievements (in addition to special occasions); 8. allow the person to relax alone; 9. validate the person's perspective and reality (even if they are the result of hallucinations/perceptions different from those of the caregiver); 10. provide a safe psychological environment for self--expression; 11. encourage the person to creativity and spontaneity and 12. support the person by allowing the individual to do what otherwise he/she would be unable to achieve.

In conclusion, the MSP and PPW set up practical references and encouraged caregivers to be more aware of their behavioral impact and to focus less on "what is done" and more on "how" it is done[25], promoting optimal levels of PCCPwD enhancing individuality, humanization and dignity[25,31].

Other influential conceptual frameworks

It is unanimous that the basis of PCCPwD is attributed to the work of Kitwood[7,14-15,42], and that its developments continue to be the essential support of the current PCCOP approach[31]. In addition, their work formed the basis for a number of other relevant developments in this area.

Table 1 presents a chronological systematization of the main contributions.

Table 1 – Chronological systematization of conceptual contributions from PCCOP.

Author(s)	Contribution
Adams and Clarke (1999)	Recognized the importance of partnerships in care: they allow direct involvement in decision making by people, families and caregivers, based on reciprocity, sharing and collaborative relationships[10].
Epp (2003)	Named as main elements: focus on the person; emphasis on unique stories and preferences; exclusion of inhumane practices; maintenance of dignity/autonomy and centrality of relationships[10,36].
McCormack (2003)	Emphasized the need for caregivers to particularize the person's unique meaning and to establish a partnership. The author defended as fundamental principles that all individuals have dignity, autonomy, values, meanings and a set of visions, stories, principles, moral desires and abilities[10,15,31,40,43-44].
Nolan, Davies, Brown, Keady, and Nolan (2004)	Defined the "senses framework": subjective/perceptive dimensions of the intrapersonal experiences of providing/receiving care[15,31,42]. They argue that for there to be quality care, the agents involved they must experience sensations of: security, belonging, continuity, usefulness, purpose, achievement/progress, importance and understanding of what happens. The analysis of these factors, allows to obtain a global perspective of the care and to facilitate a good cooperation[15].
Brooker (2004, 2007)	Decomposed the person-centered care into four elements: V: Valuing the person (regardless of age or ability) and caregivers; I: Individualize the approach; P: understand the world from the perspective of the person; and S: providing a social environment that supports psychological needs[25,30,32,40,45].
Fox *et al* (2005)	Identified seven domains, which should be promoted, to enhance well-being and a dignified life (identity, growth, autonomy, security, connection, meaning and joy)[1,10].
Edvardsson, Fetherstonhaugh, and Nay (2010)	Organized components, in residential care, identified by people with dementia, family members and employees: promoting a continuity of "me" and normality; know the person; involve the family; provide meaningful activities; be in a personalized environment; experience flexible routines and continuity of care partners[1,10,46].
Martínez (2011)	Stressed that the PCCOP are a focus of attention where the individual, starting from his self-determination in relation to quality of life, is a central and integral part of all interventions[47].

More recently, the World Health Organization[4], defined care centered on older people as a comprehensive approach based on human rights and that requires the person to be the referent and motor of the care process. Thus, organized principles about PCCOP, of which the following stand out: 1. aging is a normal and valuable part of life; 2. the person is more than his condition/illness; 3. the goal of care is to enhance capacities, self-expression, dignity and autonomy; 4. it is essential to facilitate education/information so that the person actively participates and has the power of choice in their life and care; 5. long-term care must expressly consider the perspectives, experiences, needs, expectations and preferences of individuals and 6. the person must be considered in the context of his/her life and have support in maintaining ties. In this context, in relation to caregivers, the same entity argues that they must be trained, have prestige and social recognition. The importance of sharing information, defining professional roles and working in a multidisciplinary team (organized in such a way as to facilitate potential and contributions) is highlighted[4].

DISCUSSION

The explored literature is consensual when recognizing that the principles advocated by humanistic psychology, were essential and leveraged the works of Kitwood[7-9].

Presenting PCCPwD as an approach that opposed traditional models with a biomedical focus, Kitwood reconceptualized dementia and its symptoms[11,13,22]. This process was an essential milestone and a turning point in terms of the potential for interpretation and intervention in this field. In this segment, the author coined the concept of "personhood" and, highlighting five human needs, emphasized the relational nature of PCCPwD in promoting the well-being of people with dementia[11,22,25,30-31]. Thus, it developed the conceptual frameworks of the MSP and PPW, which encourage caregivers to reflect on their care practices (and their impact). In the same context, he emphasize – through an integrative and mindful approach – the appreciation of the role of caregivers as well as their mission in enhancing the individuality and humanization of people with dementia[11,25,31,40-41].

Kitwood's work inspired a (r)evolution in care approaches. And, although the initial conceptualization was developed for people with dementia, the approach has become widespread for the care of older people (regardless of their diagnoses), particularly those living in long-term care institutions[18].

The exploration of the results obtained in this narrative review, suggests that the evolution of the PCCOP has been varied and constant. Although there is no universal, accepted and unified definition[48], through the analysis of the influential conceptual frameworks, the special relevance dedicated to the study of the values, elements and guiding principles of philosophy, practices and quality of care is highlighted.

Evidence suggests that, currently, person-centered care represents the highest standard of quality in terms of gerontological care[4,8,18]. This advance is significantly important and demonstrates a consistent investment in ethical care, a deep understanding of human beings and respect for their rights and well-being. So, it represents an influential motivation in cultural change towards improving the quality of care[18,33].

It is in the same context that the "World report on aging and health"[4], warns of the urgent need to promote comprehensive actions on the aging of the population and states that the strategy is to foster a paradigm shift by transforming the systems that guide curative models in PCCOP systems. In this sense, the same entity says that long-term care systems vary considerably between countries (e.g., due to cultural preferences, available resources and infrastructures). Therefore, it recommends that: "Although there are major knowledge gaps, we have sufficient evidence to act now, and there are things that every country can do, irrespective of their current situation or level of development"[4:211].

Thus, in order to foster a robust paradigm shift and adapt theoretical and practical models that promote scientifically-based PCCOP, plans and policies must take into account the needs of populations, as well as the characteristics of organizations that promote gerontological care, so this factor represents a potential line of future development.

CONCLUSION

The need to evolve gerontological care models makes the current moment particularly opportune to understand the basis, development, trends and future potentialities of PCCOP.

The present study allows to conclude that there is a series of relevant advances in the origin, influence and conceptual development of the PCCOP. This multidimensional approach is inherent in the optimization of the quality of care and has numerous operational potentialities with significant consequences in terms of scientific study, conceptual development, policy definition and also in the planning, execution and evaluation of practices in gerontological services. This paradigm can contribute significantly to the advancement of care for older people.

The potential risk of bias in the selected references is a limitation of this study. This factor is inherent to the procedures of the narrative review methodology, which does not presuppose the assessment of the quality of the included documents or systematic and exhaustive analyzes. In order to overcome this limitation, we sought to provide greater objectivity, systematicity and quality through the planning and achievement of a defined and organized research process. This methodology allowed for a wide inclusion of studies as well as the comprehensive integration of information, examples and evidence. Thus, a summary of the current state of knowledge relevant to the future development of this area is available.

Ethical Disclosures

Conflicts of interest: The authors have no conflicts of interest to declare.

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