**Systematic Review**

**The experience of lived time in people with dementia: a systematic meta-synthesis**

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Short Title: The experience of lived time in people with dementia

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Abstract

**Introduction:**

For people with dementia, lived time is important to understand, as the condition affects memory, perceptions of time and life expectancy. The aim of this study was to locate, interpret and synthesise the experience of lived time for people with dementia.

**Method:**

The article presents a qualitative systematic meta-synthesis. The theoretical framework of life-worlds by Van Manen provided the context for the study. The Critical Appraisal Skills Programme (CASP) criteria for qualitative studies was used to appraise the studies. Sixty-one qualitative research studies based on interviews with people with dementia were included in the review. The analysis followed the principles of interpretive synthesis.

**Results:**

Four categories were revealed: (1) Rooted in the past – “I am the same as before”; (2) Focusing on the present – “Nobody has tomorrow”; (3) Thinking about the future – “What is going to happen to me?”; and (4) Changes in the experience of self over time – “I used to…”. The latent overall meaning was expressed as: “being engaged with the dimensions of time”.

**Discussion/Conclusion:**

The experience of lived time is an active and important one, enabling people to manage the dementia journey. Future work involving people with dementia should foreground the experience of lived time.

Introduction

Living with a chronic condition like dementia, creates new relations to time [1]. Not least because the condition is progressive and life-limiting; recent research suggests that the average life expectancy on being diagnosed with Alzheimer’s Disease, the most common form of dementia, is 5.7 years, but it can range from 1.9 to 6.3 years [2]. A diagnosis of dementia shortens life. Moreover, it imposes a new temporality in a person’s life course. Medical texts often classify this in terms of ‘mild’ or early stage (2 to 4 years), ‘moderate or middle stage’ (2 to 10 years) and ‘severe or late stage’ (1 to 3 years) [3] However, the idea of a linear stage model with average timeframes is problematic; it is too deterministic and fails to take account of the care environment [4]. Critically, from our perspective, it overshadows the understanding of people’s experiences of lived time, which are likely to vary, and change during the course of the condition.

Time is typically associated with the clock, but Adams [5] and others identify another alternative to clock time, namely temporality. Temporality is a quality that is first and foremost lived by each human being [6]. Consider, for example, how time tends to slow down when you are bored and speed up when you are enjoying yourself [7]. Temporality thus refers “to the nature or structure of time, in terms of its objective existence, its subjective experience, or both, and particularly with respect to the relations among its dimensions (past, present, and future) and the way in which it passes” [8]. Therefore, to understand the lived experience of time is to understand a critical aspect of human social life.

Dutch philosopher Max Van Manen [7], described lived time as one of four existential attributes that he believed were important to analyse when seeking to understand a person’s life world. These four attributes are (1) lived body, (2) lived others (3) lived space and (4) lived time. He conceptualised lived time as subjective time as opposed to clock time and as a category for inquiring into the ways people experience the temporal dimensions of their life. Thus, lived time, as conceptualised in this review, is more than people’s orientation to clock-time; it is also related to perceptions of time and how these might change and evolve over the course of the illness.

For people with dementia, lived time is a particularly important attribute to understand, for several reasons. First, the disease process affects the hippocampus, the ‘core temporal device in the brain’ and so perceptions of time, including one’s ‘internal clock’ are impaired [9]. This can cause practical problems, for example, someone getting up in the middle of night to have breakfast. Hence, there has been considerable work in dementia studies on assistive aids to help with time orientation [10].

Second, memory is one of the cognitive capacities most affected by dementia, and so people with this condition often have difficulties with recalling past events and the chronological order of their life. This can create, amongst other things, a significant moral dilemma for professionals who have to make best interest decisions for someone with advanced dementia - that is, deciding what *is* in someone best interests when their desires change pre-and-post dementia because the person no longer remembers what they liked and disliked [6]. Third, many people with dementia are likely to find themselves in places ruled by the clock, such as day care centres, hospitals, clinics, and care homes; even people in their own home may find their lives governed by clock-time, as home care workers have to work under strict time pressures [11]. In such situations, people with dementia are likely to feel rushed, and to experience time very differently to those who provide the care service [12].

A fourth and final reason for advancing understanding of the lived experience of time for people with dementia is because dementia is a chronic condition strongly associated with a particular time in the life course – namely ‘old age’. Consequently those affected mid-life and diagnosed with so called ‘early-onset dementia’, can feel ‘out of time’, as if things are not happening in the expected chronological order, therefore disrupting the ‘social clock’ of one’s life trajectory [13]. Analysing how different people with dementia conceptualise and perceive of time, could therefore shed fresh light on the non-linear and temporally disruptive aspects of this condition.

Understanding how people with dementia might experience lived time is important not only for the enhancement of care and time orientation, but also for the development of sociological understandings of temporality in the context of chronic illness. In one of the few empirical studies that explicitly sought to understand perceptions of time among people with dementia, the main temporal problems participants had was ‘knowing when’ and ‘knowing how long’ [14]. In this study, ‘time was experienced, by the five participants, as something internalized, well known and self-evident, as internal and external rhythms, giving structure and tempo to their daily lives’. Other researchers have collated a collection of writings on the personal meanings of time for people with dementia and those who provide care [15]. This work reinforces what many empirical studies have concluded, namely that people with dementia are capable of evolving into new and different selves over time [16-18]. All of this emphasises the significance of investigating dementia temporalities.

Social science literature on the experiences of lived time for people with dementia is limited, possibly because those without dementia do not realise how important temporal experiences are to those living with the condition. In recent work on social health and dementia involving a team of professional academics and clinicians, it was not until the team sought feedback from people with dementia that the concept of time was given consideration. As the researchers note, a recurring topic in their feedback was the importance of time and how the idea of change over time should be given more attention [19]. Given how important the experience of lived time clearly is to people with dementia, there is a need for a systematic review that synthesizes the knowledge on this topic. Thus, the aim of this systematic synthesis was to locate, interpret and synthesise the experience of lived time for people with dementia.

Methods

We performed the same methodological approach as for two previous published articles in this set of articles based on the theoretical framework by Van Manen [20, 21]. By a systematic literature search combining terms with a variety of combinations of dementia and experience, we screened five databases: Age Line, Cinahl Complete, Embase, Medline and PsycINFO. The complete search strategy is shown in table 1.

We included peer-reviewed qualitative research studies published in English between January 2004 and February 2020. We identified 7840 articles and 200 articles were read in full text. Further details on selection criteria are described in the flowchart is shown in Figure 1.

Figure 1: Flow chart, literature search

To ensure rigour and quality, we performed a paired screening, i.e. two authors read the articles in full text and came to consensus for further inclusion. Potential pair-disagreements were to be discussed with the whole author team. Articles were included if the sample comprised people with dementia, the data was collected from qualitative interviews and the article contained quotes or statements relating to the concept of the concept ‘time’. In cases of focus groups or dyad interviews were spouses or health care personnel were present during the interviews, the article had to describe the people with dementia’s voice explicitly. We excluded articles that a) had a mixed sample including both people with dementia and people with other diagnosis b) had sample of people with an unclear, probable or possible dementia diagnosis c) described experiences that were based on an intervention d) were based on single cases. The quality process described here is in line with the PRISMA guidelines [22].

**Quality assessment of the studies**

A total of 69 articles were reviewed in consistence with the CASP (Critical Appraisal Skills Programme) criteria for qualitative studies [23]. All the included articles were assessed according to the CASP criteria by two authors. Any disagreements were to be discussed with the other authors to reach consensus. Nine criteria of the CASP were used in the assessment part, all given 1 point if satisfactory stated: (1) a clear statement of aims; (2) appropriate choice of the method; (3) appropriate research design; (4) congruence between the recruitment strategy, aims and research; (5) the data collection method addresses the research issue; (6) a relationship between the researcher and the participant was considered; (7) ethical issues were considered; (8) the process of data analysis was sufficiently rigorous; and (9) a clear statement of the findings. By such the maximum score was nine for each article, leaving the top score with the value of high methodological quality, while the score of 7-8 points gave a value of moderate quality. Only studies valued to moderate or high quality were included as shown in table 2. As a consequence of this quality assessment 9 studies were excluded due to low quality, i.e. values below 7.

This meta-synthesis incorporates 61 articles where 762 people with dementia represent the total sample as shown in table 3. Thirteen of the articles reported the persons’ stage of dementia or description of their cognitive function and 27 articles described the type of dementia. Fifty-one studies served with information about the participants’ living conditions and care facilities, 32 studies explicitly described that the participants lived in own homes, and 12 studies included people living in nursing homes or other care facilities. Data was obtained mostly from individual interviews (51 studies). Eight studies draw data from interviews with people with dementia, their dyads or pairs, and in two of the individual interviews, a caregiver was present. Five studies based their data from focus group interviews. Most studies were cross-sectional with one single interview, however 18 studies conducted repeated interviews, of those, two studies carried out interviews over more than 1 year.

**Data abstraction and meta-synthesis**

For this meta-synthesis, the data abstraction was conducted in line with the principles of an interpretative synthesis [85]. The initial procedure was to create concepts from the data gathered from primary studies. Further we gave attention to specific theories that integrated the concepts [86]. We were inspired by qualitative content analyses [87]. This particular analytic process comprised five steps: In the *first step*, pairs of authors (SE, TLI and EKG) read all the included articles and extracted text that described ’time’. The extracted text constituted the “meaning units”; a form created for further analysis. The *second step* incorporated condensation of meaning units (AMMR and SE), where the content of the direct citation was extracted using the meaning unit’s own language as shown in table 4. Next, we labelled the condensed meaning units with codes to organize the material (AMMR, RB and SE). In the *third step* the codes were compared and gathered into four preliminary groups of categories (SE and EKG). In the *fourth step,* two authors (AMMR and RB) further identified similarities and differences to make a structure and thereby gathering the codes into subcategories and four categories that presented the manifest meaning from the analysis. The categories were discussed by all the authors. The *fifth step* gave a *comprehensive understanding* of what we summarized and reflected upon from the findings consisting of ’time’ to give a description of the content as one overall latent theme (all authors) [87].

Findings

The analysis revealed four categories as presented in table 4: (1) Rooted in the past – “I am the same as before”; (2) Focusing on the present – “Nobody has tomorrow”; (3) Thinking about the future – “What is going to happen to me?”; and (4) Changes in the experience of self over time – “I used to…”.

**Rooted in the past – “I am the same as before”**

People with dementia will often lean towards the past to make sense of their current situation. Rooting themselves in the past by looking back and reliving events seems to make it easier to accept their life situation and compensate for losses. As one participant says: “I’ve faced quite a few challenges in my 90 years. So, I’m not letting this bother me. I think one just has to assume that everything’s going to go well, and it probably will go well…I’ll survive. I always have” [25]. Looking back helps individuals to cope with the here and now. They have managed their lives in the past and so they trust that they are able to manage and cope with their ongoing lives as well. The experience of themselves as the one they have been also seem to confirm their self-identity at present. As one participant says, “I am the same as before” [73]. Another participant states that you must “cling on to who you are” [34] which indicates that the past becomes an important source of identity. Narrating memories of achievements gives satisfaction and highlights positive aspects of life. Moreover, leaning on positive experiences from childhood and previous roles and statuses, serves as a reminder of identity and can help a person to feel in control. As one participant says, “doing what I have always done helps with staying in control of the situation and maintaining identity” [81].

Everyday occupation seems to lead to a sense of coherence associated with aspects of time and existence for people living with dementia. A person wants to be accepted in terms of their changing abilities and for who they were in the past. One participant says, “People should be allowing us to do as much as we can for as long as we can. To the best of our present abilities” [41]. For many participants the need to be persistent in their effort to keep going is illustrated in the following quotations; “I try to do everything possible, as long as I possibly can” [30] and “I’ll still be energetic and not give up… I am not going to just sit down” [73]. Several participants mention the importance of staying engaged and look for new meaning in familiar routines like walking the dog, exercising or caring for the family. Some participants are grateful to have their current abilities, as illustrated in the following quotation, “anything I can still do and function with I appreciate the value of far more than I did before” [41].

Life continuity, as in being the same person as before the diagnosis, is important. Holding on to religious activities and to reminiscence familiar and mutual memories is a way to keep connected with the past. One participant explains how engagement with the church contributes to a picture of continuity in the lives of people living with dementia, in which purpose and activity can remain, even alongside the challenges that the condition can create [52]. The internalized hope, embedded from childhood, enable people with dementia to live in present and face the future. Rooting themselves in the past, help to maintain personhood.

**Focusing on the present – “Nobody has tomorrow”**

By focusing on the present, people with dementia can simultaneously leave the past behind and avoid thinking about the future. Living with a progressive, terminal disease, enhances the need to live in the moment, as one’s future no longer is certain. One participant says: “we are just trying to live through the present day and for all good things that we have today, because nobody has tomorrow. That is my motto now. We all have only today” [70]. Many of the articles reveal that participants prefer to focus on the present. Some feel that there is no need to plan ahead, as long as the situation is stable; take for example, these participant comments: “We take it as it comes and we make the best of it” [30], and “well I just live for today …. I just think we can put it right, tomorrow’s another day …. I only know today at the moment. I haven’t a clue about tomorrow …. I don’t get down about it …. I don’t worry about it» [63]. Clearly, it is important for some people with dementia to focus on the present.

Living in the present seems to be a way of coping with uncertainties about the future. Some participants speak about how they used to feel terrified and have nightmares about the future but feel calmer now that they have learned to focus on the present. Others find relief in trusting family members to take good care of them as the condition progresses as illustrated by one participant who says: “I found that it is no use worrying, as I believe my sister and my children will look after me even at the worst stage. For now, I only wish I can continue to live each day as it comes” [65]. Also delaying telling people about the diagnosis is a way of putting one’s problems on hold. One participant shares his reflections about being open about his dementia diagnosis: “I thought there is no point in saying anything until… later on is in plenty of time, there is no point in worrying them all starting now you know” [88]. This illustrates that even though they are aware of the future and what might happen then, they choose to live “here and now”.

Focusing on the present involves keeping track of clock time using memory aids like books, calendars, digital clocks, text television, or in one case, a mechanical egg timer [69]. For some people with dementia, the everyday life can feel tedious, as illustrated in the following quotations: “It’s a bit boring just sitting here, I’ll be sitting here now until tea time” [66] and “I sit a lot and wait, but I do not know what I’m waiting for” [73]. Waiting for things to happen seems to be a common experience for participants in many of the studies.

**Thinking about the future – “What is going to happen to me?”**

Some people with dementia spends time thinking about the future. They perceive the future as a time of uncertainty and inevitable demise as one says: “It is going to get worse- that’s the problem” [76]. For another participant, it is her sole concern, as she says; “the only thing that what worries me is my future and what is going to happen to me” [34]. Other participants express more specific concerns about the future, such as money, being a burden on their family, and their changing health status and care needs. For example, one participant says, “we always had plenty of money, then suddenly we had no money and you start thinking about the future.” [32]. Another participant worries about how much help she will need from her spouse. She says, “I just worry about the sort of burden I’m going to be on my husband.” [24]. Another participants are fearful of the future because they imagine that they will be forgetful all the time. They said “I can’t remember what I am doing and, in the future, I’m going to be like this all the time. It is frightening”. For another participant such demise mark the end, saying, “when it gets to the point that it is obvious to the casual observer that I have dementia, I am done” [72]. These data highlight how people’s experiences of dementia are sometimes orientated towards the future.

Thinking about the future means thinking about one’s own deterioration and death. For some participants, this means taking practical steps in an attempt to either stop time or plan for the future. For example, participants in one study say that they take medication to hold back future time [38]. Others speak about making a will or planning their funeral. For example, one person says: “my son has got the details and the papers for the funeral people. I don’t want the children fighting because they must pay. I wanted to do it myself.” [45]. Other participants think about their future in an existential way; one participant says: “What is the point of prolonging life? Life is a hell both for me and for others” [55]. Participants in three other studies report that they have had thoughts about suicide because they feared what was coming [38, 45, 47]. For one participant in her 90s, who believes in heaven, death cannot come soon enough; she says, “I can’t wait to get there. I’m waiting, I’ve had a good life.” [35].

Some participants think more sanguinely about the future; or they choose not to think about it all. They are inclined to accept the situation and to remain hopeful. For example, one person says, “I just think it's one of those things….okay it's a problem but it's not the end of the world and I don't think about it.” [79]. Participants in another study report that they tackle life with dementia by maintaining positive attitudes towards their present and future [43]. One participant says: “I keep saying I want to go into care sooner rather than later” [75]. Other participants said that they told themselves to ‘‘look forward, don’t look backward’’ [39]. In these instances, thinking about the future is a positive orientation.

**Changes in experiences of self over time – “I used to …”**

People with dementia notice changes in their experiences of self over time. The phrase ‘used to’ features a lot in the data, as participants describe how their character have altered over time due to the dementia by losing track of time [46] or forgetting what to do [82]. For example, in one study, a woman says, “I used to be a hard-working person, but it’s all changed. I’m no longer interested in doing anything” [70]. Another person says, “I used to be very efficient, very… exact. I knew exactly what I was doing.” [41], and another remark that, “as a person, I always used to be in charge of what we were doing and everything . . . but I couldn’t do it now . . . it’s terrible.” [63]. Others feel that they are no longer as useful or worthy as they used to be. As one participant says, “you’re not as good as you used to be” [24] and another reflects that, “I used to be one of the top a medical professionals with executive responsibilities and was quite an important person” [40]. Some participants speak with frustration about how their current self is fundamentally different to their former working self. As one participant says, “I don’t act like an active person anymore: When I was employed, I worked from 8 am until 12 midnight; not now, why should I be like this? Why?” [62]. Some participants experience these shifts in self as a loss. One person says: “everything is gone. I have lost those times (past life).” [64]. These data show how acutely some people with dementia experience changes in themselves over time.

Many people report functional changes and a significant difference in their everyday routines and priorities over a certain period. This is often due to changes in cognitive self. For example, one participant who likes to do crosswords and competitions in a weekly magazine for ‘brainwork’ have noticed how much longer it is taking him to do them. He says, “six/eight months ago, I'd go through it in two days. It's taking me seven days now.” [79]. Another participant says that “I can’t even write my name and I used to do it regularly, you know, three months ago” [34]. Someone else have noticed a change in their abilities in a relatively short space of time. They say, “it only became a problem within the last year. I think there was something wrong before that, but it didn’t affect my life.” [58]. Changes in perceptions of self over time, means that some people are no longer being able to do practical things for themselves at home anymore, such as getting dressed [50], following a recipe [41] and using the stove [37]. One participant is frustrated about the need for a driving test to continue driving: “It was like a bombshell … terrible at the time” [77]. Another person has changed their shopping routine due to changes in how they feel when they are out; they say, “I am more stressed when I go shopping, so I go to the shop early in the morning.” [31].

Not all participants experience a change in themselves; some feel that some things are still the same, or that any changes are caused by their advancing age rather than dementia. One participant makes this reflection: “I don’t think I have changed, I’m just the same. I wouldn’t drive as far as I use to, but I do drive. I do perhaps get a little bit anxious… It’s all right, I am getting older anyway.” [29]. Similarly, another participant says, “I can still read, write and do other things, you know” [28]. In another study, a participant stats that he ‘naturally’ is still gay after the dementia diagnosis [27]. These are important data, as they show how some people believe that they “remain the same person despite the influence of dementia” [79]. One participant tries to keep in control: “I hope they haven’t recognized that I’m changing … so, I’m doing my best to keep myself under control.” [74]. Overall, the analysis indicates that a change in the experience of self over time is common for people with dementia.

**Overall theme**

An overall synthesis of the categories generated from the included articles reveals the

comprehensive understanding and the latent meaning expressed as: “being engaged with the dimensions of time”. Together, the four categories (1) Rooted in the past – “I am the same as before”; (2) Focusing on the present – “Nobody has tomorrow”; (3) Thinking about the future – “What is going to happen to me?”; and (4) Changes in the experience of self over time – “I used to…”, show that people with dementia experience changes in self related to all three dimensions of time; past, present and future. Thus, the experience of lived time is an active and important one, in terms of enabling people to process and manage the dementia journey.

Discussion

The aim of this study was to locate, interpret and synthesise the experience of lived time for people with dementia. People with dementia, especially older people, are often assumed to live in the past but our findings show that this is not the case. The main findings indicate an experience of being engaged with all the dimensions of time - the past, present and future. According to Van Manen [7], lived time is an integral part of the human experience, and it is important that we take time into account when seeking to understand a person’s lifeworld. In doing so, we can generate deeper insights into the fundamental existential experiences of a person’s life, including how they make sense of life and death.

Participants in the studies we reviewed make a deliberate effort to engage with the different dimensions of time. They are consciously engaged in what sociologists have called “time work” – that is, endeavouring to construct one’s own temporal experience [89]. For instance, consider the efforts participants in the included studies make to live in the present and to avoid talking about the future. They work on taking things “one day at the time”, as people so often do when faced with unexpected life course transitions [90]. In this sense, the dynamic of time influences how people with dementia process and manage the condition.

Sometimes people liked to root themselves in the past to help maintain their personhood. This confirms what other researchers have found; that time and personhood are inevitably intertwined for people with dementia [91]. According to Flaherty “time work functions as a temporal lathe with which to modify the contour of one’s personal experience” [89]. It involves agency and self-determination; attributes that people with dementia are not always seen as having, but which become apparent when analysing the subjective experience of time.

As shown in this study and others, people with dementia are capable of evolving into new and different selves over time [18]. Following a diagnosis, people with dementia can and do incorporate a ‘manageable disability identity’ into their existing identities [17]. However, as the findings of this study indicate, the lived experience of this process is not necessarily an easy or comfortable one. Thinking about the future, and what might happen, and reflecting on how one used to be, can be incredibly difficult for someone with a life-limiting, neurological condition like dementia. Hence, people often choose to engage with the present (rather than the past or future). In this regard, people with dementia can remind us of the value of living in the moment and “slowing time down”.

Research within the field of critical disability studies has emphasized the importance of understanding lived time from the perspective of those living with impairment and disability. By focusing on the temporal aspects of life with dementia, as we have done in this study, important questions are raised about how temporal norms (such as valuing speed) may be adversely affecting the lives of people with dementia. For example, are people with dementia disadvantaged by temporal norms around communication, in the same way as people with a speech impairment associated with other disabilities reportedly are? [92]. Our findings would suggest that they are, as whenever people engage with the dimensions of time, they often do so in relation to perceived temporal norms. Thus, experiences of lived time can be an indicator of social exclusion. The experience of lived time can be seen in relation to the neurological concept of “mental time travel”, which refers to our cognitive ability as human beings to travel back into the past in our minds or imagine ourselves in the future. A temporal agentic practice is often overlooked by care providers, as well as researchers in the field of dementia studies. Yet, as our study shows, people with dementia are engaged with the dimensions of time for much of their daily lives. As Van Manen [7] argues, lived time is a key structure in our lives, no less so for people with dementia.

Our study has implications for dementia care practice and research. In practice terms, family and healthcare providers must be aware of their important role in improving people with dementia’s lived experience of time. Not only in terms of time aids, such as speaking clocks, but also, and perhaps more critically, by making time a more explicit framework for intervention work. Dementia care practices are either past-orientated (e.g. reminiscence therapy, life history work), present-orientated (e.g. time aids, living in the moment) or future- orientated (e.g. advanced care planning, rehabilitation). Given the findings of this study, each one is vital for improving people with dementia’s lived experience of time.

Research wise, our meta-synthesis has the potential to inform future scholarly work on time ethics – a construct developed by Norwegian researchers in relation to people with dementia in care home [12]. Time ethics denote a flexible time culture and carers working to a ‘sovereign time rhythm’ – that is, providing care in a way that they themselves define as good, rather according to the clock or using time as a stressor [12]. Our study brings to the fore, people with dementia’s lived experience of time, which is critical from an ethical perspective, as we need to know *how* people with dementia experience and are affected by time culture. Note, however, that we had to extract the data on time: none of the included studies set out to investigate peoples’ temporal experiences. Thus, future work on improving the health and wellbeing of people with dementia in support situations should foreground the experience of lived time and time ethics.

**Strengths and limitations**

The main strengths of this meta-synthesis are that (1) by combining studies we have investigated the lived experience of time among a relatively large cohort of people with dementia and (2) it only included interview-based studies involving people with dementia. The limitations are that the experiences of people with more advanced dementia are excluded and the lack of information in reviewed studies on the experiences of men and women with dementia from black and minority ethnic communities. Furthermore, we recognise that informants in interview-based studies are individuals who are willing and able to talk about their condition. Given these limitations, it is not possible to extrapolate findings to the entire dementia population.

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**Statement of Ethics**

Ethical approval and consent to participate has been gathered from the researchers responsible for each single study included in this meta-synthesis. As this is a literature review, ethical approval and consent to participate was not applicable.

**Conflict of Interest Statement**

The authors declare that they have no conflicts of interest.

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**Author Contributions**

All authors took part in the critically review and analysis of the data. TLI, EKG and SE read all articles in full text. EWT, EKG and SE made the quality assessment, AMMR and SE made condensation of meaning units and AMMR, RLB, EKG and SE further organized the meaning units into groups of categories, identified similarities and differences to make a structure of the codes into subcategories and categories. The categories were discussed by all the authors. SE, RLB, EKG and AMMR wrote the article in cooperation with the other authors. All authors have read and approved the final manuscript.

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