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Title page

Parkinson's disease: A pragmatic portrait of daily life from the patient's perspective.

A systematic review of qualitative research.

Running head: PwPD's daily life with Parkinson's disease

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Abstract

Purpose: Parkinson's disease (PD) is a complex chronic condition. How do people and spouses, experience their daily life with PD?

Methods: A systematic review of qualitative research was conducted in 2019 by screening: PubMed, Google Scholar, Persée, Lissa, PsychInfo, CINAHL, EBSCO, and Cairn.

Results: 41 qualitative research projects were included, using ethnography, focus groups, in-depth interviews, diaries, protolanguage, and storytelling. 764 people with PD and 75 spouses from 14 different countries talked about their experiences. Important dynamic bio-psycho-social life changes are experienced from the first symptom on: uncertainty, time-management, the dilemma of accepting help or not. People's care priorities are based on individual daily life needs which are not just illness-, but person-related, concerning all aspects of life.

Conclusion: This review draws a realistic portrait of the PD daily life experience to provide global understanding and encourage needs based person-centered care. A pragmatic model of the dynamic daily life experience is presented.

Keywords: Parkinson's disease, illness experience, daily life, pragmatic approach, qualitative research, clinical practice, person-centeredness, integrated care

1.Introduction

Parkinson's disease (PD) concerns 10 million of people worldwide (Statistics 2019). That complex chronic condition affects all aspects (bio-psycho-social) of a person's daily life. In times of growing effects of *health democracy*, people with Parkinson's disease (PwPD) become active manager of their personal healthcare pathways. Therefore, healthcare must be holistic and person-centered to meet PwPD's real needs in daily life (Buet. A person-centered approach takes into account the biomedical-psycho-social dimensions, including beliefs, desires, and capacities of a PwPD and integrates the shared decision making to optimize the holistic multidisciplinary accompaniment and an effective therapeutic alliance on a long term.

To identify these perceptions, qualitative research exploring the perspective of PwPD is useful and appropriate. An interpretative study of the day-to-day demands of PwPD revealed that healthcare professionals (HCP) tend to show a lack of acknowledgment of personal concerns related to PD (Habermann 1999). Practitioners were considered to be essentially illness-, but not person-centered, focusing especially on medical prescriptions. A discrepancy between experts' prediction and PwPD's real-life illness experience exists (Buetow et al 2008).

2. Aims

The purpose of this study is to draw a realistic portrait of the PD daily life experience to provide all the multi-disciplinary actors (including non-healthcare professionals and spouses), involved in that complex healthcare pathway, a better global understanding of the real-life condition with PD. That global portrait could be a common base of information through which HCP are encouraged to deliver more needs based person-centered care to the PwPD population and to optimize the therapeutic alliance and the multidisciplinary holistic support on the long term.

3. Material and Methods

How to dress a realistic portrait of one's daily life? Sztompka (2008) describes *the anatomy of daily life* in 7 dimensions. According to him, daily life is:

1) The observable manifestation of social existence, always including relationships with other people (even just virtually present in our thoughts, memories, dreams) in a social context, during which 2) events are repeated, not unique, but cyclical, rhythmic, or turning into routines, including 3) rituals, following certain un-reflexive, deeply internalized scripts such as reading the newspaper during breakfast. Daily life engages 4) the body and emotions, is usually localized 5) in space: at home, or outside, while the character of the site significantly determines the character, style, form and content of social events, and 6) in time, while we distinguish the *short term* (episodes of daily life have a certain temporal duration) and 7) *the long term*, during which daily life flows un-reflexively, following habits and routines of which the actors are not fully aware.

Our multidisciplinary research team (3 general practitioners, 3 neurologists and a sociologist) decided to perform a systematic review by a pragmatic approach of daily life, based on a typical day and its repeated routines. We aimed to identify PwPD's difficulties and challenges to get insight into their unmet needs and to provide HCP that information to foster multidisciplinary person centered and needs-based support.

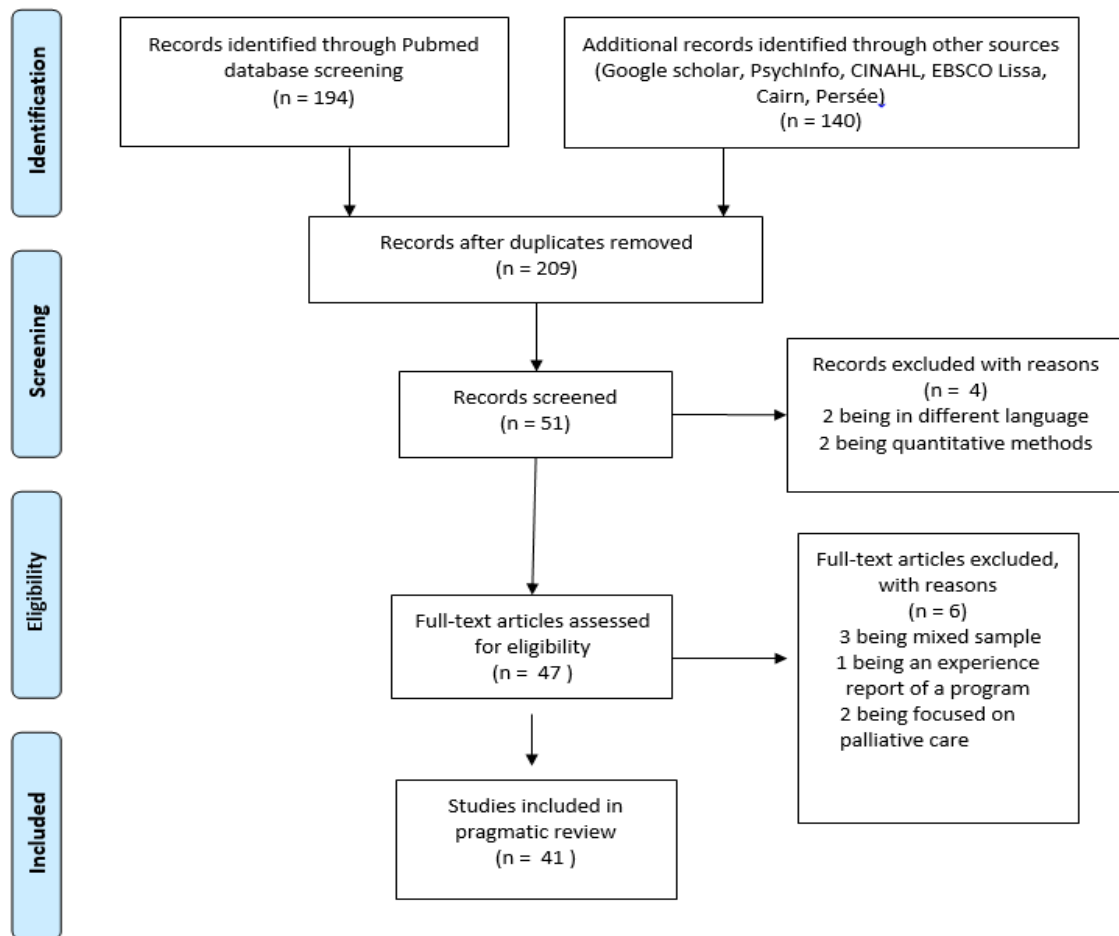
In January 2019, PubMed, Google Scholar, PsychInfo, CINAHL, EBSCO, Persée, Lissa and Cairn were screened. The MeSH terms were used: Parkinson's disease OR Parkinson AND daily life OR daily living activities OR lifestyle AND experience AND needs AND qualitative research OR ethnography OR focus groups OR in-depth interview OR diaries OR photo language OR diaries OR storytelling. Articles had to be written in English, French or German, and to fulfill at least 20 items of the 32-items COREQ criteria (Tong et al. 2007). Inclusion criteria were defined as followed: Articles had to focus exclusively on PwPDs' daily

life challenges, such as the impact on their intimate relationships and dyad problems with PD, and use a qualitative research method (interviews, focus-, or nominal groups, photo voice, diaries, led by sociologists, psychologists, nurses, or physicians (neurologists, geriatricians, and general practitioners) to get an exhaustive PwPD's perspective of daily life. Studies using quantitative research methods (surveys and quality of life score analysis), focusing on PwPD's well-being or quality of life, daily life problems related to deep brain stimulation or other invasive treatments, and reviews or meta- analysis were excluded.

4. Results

Altogether, 41 qualitative research articles were included (Figure 1; Table 1).

Figure 1: The Flow-diagram of the review

Figure 1: Flow Diagram of the review**Table 1:** Overview of the included 41 studies in order of their year of publication

Nijhof G.	1995	NL	n = 23 (10 F)	Storytelling, Interpretative Phenomenology	Dissociation of private and public life (shame)
Habermann B.	1999	USA	n = 16 (7 F)	SSI, narrative interpretative inquiry	Ability to cope to preserve the inner self before PD to maintain intact identity
Sunvisson H.	2001	Sweden	n = 11	IDI, PH	A suitable environment opens opportunities for managing daily issues
Fleming V.	2003	UK	n = 19 (19 F)	Diaries, IDI, FG, IEM (Boddy/Rice)	Impact on inter-, intra- extra- and meta-personal womanhood
Low J.	2004	Canada	n = 14 (7 F)	SSI, GT	PwPDs are hiding complementary treatment strategies
Whitney C.	2004	USA	n=12 (6 F)	Storytelling, Interpretative Phenomenology	PwPD who are able to identify markers of continuity maintain their quality of life
Bramley N.	2005	UK	n = 1 (1 F)	Ethnography/case study, PH	Impact on self-esteem and agency of identity-shift
Phillips L.	2006	USA	n = 11 (5 F)	IDI, QCA	Advices given by PwPDs to others to manage daily life with PD
Dressen C.	2007	France	n =14	SSI, FG, QCA	Spouses can feel lonely, helplessness and guilty
Solimeo S.	2008	USA	n = 4 (2 F)	Illness narrative SSI, QCA	Gender effect in illness experience
Oehlberg K.	2008	USA	n = 38 (15F)	Open-ended questions, QCA	Guarded anticipation, becoming informed, later disease dynamics and negotiation with Mr Parkinson

Haahr A.	2010	Denmark	n= 11	SSI, PH (Van Manen method)	The body is setting the agenda, permanent struggle for time, experiencing dependence and compromise
Chiong-Rivero H.	2011	USA	n = 62 (26F) 15 spouses	8 FG, SSI, QCA	Clinicians should elicit more information about feelings such as embarrassment, shame, humiliation, and stigma
Martin S.	2012	USA	n = 44 (23 spouses)	IDI, GT	Dramatic psychosocial challenges in a dyad
Kleiner-Fisman G.	2013	Canada	n = 13 (7 F)	Nominal groups, QCA	Coping in daily life is more important than PD knowledge
Liao YC.	2013	Taiwan	n = 15 (6F)	IDI , GT	Each evolution stage causes specific needs
Eriksson BM	2013	Sweden	n= 11	IDI, GT	Keep moving to retain the healthy self
Barken R.	2014	Canada	n = 8 spouses (4 F)	IDI, SIA	Caregivers time-management impacts their biography
Kohler M.	2014	Germany	n =8 PwPD n= 6 spouses	SSI, QCA	Effects on the changed move patterns and coping skills
Soleimani MA.	2014	Iran	n = 10	IDI, GT	PD disrupts social connectedness
Hammarlund CS.	2014	Sweden	n =11 (4 F)	SSI, STC	Being able to walk independently is a prerequisite for autonomy and participation in society
Olsson M.	2015	Sweden	n = 9 (9 F)	Life - world Led, PH (epistemology)	Being able to move; being director of one's own life

Shin JY.	2015	USA	n=16 PwPD n=5 spouses	SSI, QCA	Medication responses, costs and forgetfulness influence medication adherence
Hermanns M.	2015	USA	n = 9 (7 F)	Photovoice, QCA	“Staying determined,” and five sub-themes “staying active,”
Murdock C.	2015	UK	n=10	IDI, PH	Occupation is experienced in a positive way in psycho-social, spiritual, and physical dimensions
Smith L.	2016	UK	n = 9 (5 F)	Life - world Led, GT	Identity-shift as a coping strategy
Gibson G.	2016	UK	n = 15 (15 M)	Body lived experience, IDI,GT	Need to consider lived experience of medication usage
Mullin L.	2017	UK	n= 17	SSI, GT	Being able to control and feeling under control PD impacts workplace success
Hurt CS.	2017	UK	n= 18 carers	SSI, QCA	Uncertainty is experienced by carers in parallel to PwPD
Shapira AL	2017	Israel	n=78 (39 M 34 F; 5 N/A)	Netnography/ Illness blog analysis, QCA	PwPD share all the dimensions of their daily life with PD with peers on blogs
Lutz S.	2017	Canada	n = 6	Visual narrative inquiry, Occupational perspective	Interrelationship between occupation and identity
Parry R.	2017	France	n = 1 (1F)	IDI, Neuroergonomic perspective (ethnography)	3 axes of motor activity (medication cycle, person environment, complex situation)
Ravenek M.	2017	Canada	n=39	(FG, IDI), GT	Illness-related uncertainty impacts age-graded life path

Mohammad S.	2017	Jordan	n = 8	SSI, QCA	Importance of early acceptance, family, spiritual support
Vann-Ward T.	2017	USA	n = 25	IDI, GT	Clinically derived theory of <i>Preserving-Self</i> to help health care provider to offer real person-centered care
Hammarlund C.	2018	Sweden	n = 19	IDI, GT	Based on self-determination theory, PwPD face a shift between internal and external locus of control, balancing between a web of needs and demands
Sperens M.	2018	Sweden	n = 24	IDI, GT	Struggle with medication regime and ongoing ability changes. Need for joyful occupations to attain a satisfactory daily life.
Jonasson SB.	2018	Sweden	n=12 (6 F)	SSI, QCA	Experience of fear of falling is complex and varies in time and space
Valcarenghi RV.	2018	Brazil	n=30 (19 F)	IDI, GT, SIA	PD impacts the psycho-socio-cultural dimension of an individual
Gardenhire J.	2019	USA	n= 85	IDI, GT	Reframing optimism as a choice rather than feeling favors the progress on the journey to optimism
Maffoni M.	2019	Italy	n= 27	IDI, GT	Past, present and future: experiencing PD over time

In grey the studies in common with Soundy et al.,

GT= Grounded theory, PH= Phenomenology, QCA= Qualitative Content Analysis, Symbolic Interactonism, STC = Systematic Text Condensation SSI= Semistructured interviews IDI=In depth interviews, FG=Focus Groups

4.1 Study population

764 PwPD and 75 caregivers from 14 different countries talked about important daily life challenges. The gender of PwPD and spouses was not always indicated. For PwPD the gender was declared as *male* for 203 and *female* for 209. The gender for 38 spouses was *female*. Based on their stories, we will now draw a realistic portrait of peoples' daily life with PD, based on the key elements of Sztompka's (2008) *anatomy of daily life in 7 dimensions*.

In that context, we chose to present our findings, following one's body and emotions, engaged in a social context, evolving in time and space. The time axe includes the short term (daily life) and the long term (the life course). According to our findings and inspired by *the ecological system theory* of Bronfenbrenner (1986), we distinguish here three social dimensions on the space axe: the *microcosmos* (PwPD+/-spouses at home), the *mesocosmos* (relationship and social activities with others than spouses at home or outside), and the *macrocosmos* (the social existence in a global social context, including external threats and constraints which can't be actively influenced by PwPD).

4.2 *Microcosmos*

4.2.1 *Body and emotional experiences with PD in a social context*

PD creates turbulence in all dimensions of daily life and affects the PwPD's personal, couple, and family life in a holistic way (bio-psycho-social).

With the appearance of symptoms (motor- or non- motor), PD impacts peoples' physical health before the diagnosis, and before the first visible symptoms involuntarily exposes them to other gazes, staring at them, and impacting the PwPD's psychological health prior to PD.

But even when PwPD have already noticed some loss of body control, the diagnosis announcement, "*dropped like a bomb*", is a violent experience (Phillips 2006), damaging previous physical life- and inner-self experience (Smith & Shaw 2016):

“Like a bird with a broken wing.”

PwPD feel trapped in their own body and unable to follow their previous course of life (Bramley & Eatough 2005):

“You have to tell your body what to do, it doesn't just doing it by thinking.”

In later stages, PD changes moves, generates near falls and falling so that a stress and a fear of falling appear which often leads PwPD to avoid going out and to a restrain social life (Hammarlund et al. 2018; Soleimani 2014).

According to Jonasson et al. (2018), fear of falling disturbs daily life because of an awareness of the risk to fall and therefore a feeling of vulnerability in daily activities and everyday environments which seems to become potentially hazardous. PwPD realize the loss of what once was and what could have been. In consequence they adopt strategies to cope with fear of falling through adapting activities, avoiding them, or to perform them with some help.

Staying active (body and mind) was found to be an important theme (Jonasson et al. 2018; Sunvisson 2001; Hermanns 2015; Eriksson et al. 2013; Parry 2017; Hammarlund et al 2014). Eriksson et al. (2013) identified *“Keep moving to retain the healthy self”* as the continuing process of maintaining functions and activities in the individuals' lives through exercise. To start and maintain exercise habits, two motivations were identified: *“Having explicit life goals and having confidence in one's own ability”*. Exercise was performed to *“take rational position, to slow progression, to achieve well-being, and as a coping strategy”*.

According to Hammarlund (2014), the ability to walk has a complex and multifaceted impact on PwPD, including physical, psychological and emotional aspects as well as on the ability to be active in daily life and to participate in society and appears to be intimately linked to an individual's social identity, emotional well-being and integrity. Being able to walk independently is a prerequisite to an autonomous life and participation in society.

Communication is also an essential element of active social life. PD affects communication skills and therefore social life.

“...they told my children... to tell me that [...] we don't understand what he's saying so there is no point calling...I understand that... I find it equally embarrassing.” (P 9) (Hammarlund 2018).

Handwriting for instance is a form of alternative communication which allows PwPD to stay in contact with others when they can't go out anymore or, in the case of physical disability, psychosocial discomfort, speaking problems during phone calls, or even in front of partners or caregivers. When PwPD stop handwriting, they start writing e-mails or SMS to communicate before they stop all forms of communication due to the illness-evolution. Losing handwriting can therefore be the beginning of a process leading to social isolation, which reveals the importance of communication skills and their interrelation with physical disability and psychosocial well-being (Hammarlund 2018). Depression (Oehlberg 2008) and cognitive impairments were negative emotional experiences and described as *“some chaos in the brain.”* (P1) (Hammarlund 2018) or fear about dementia: *“The scariest thing is that dementia. Sometimes I forgot the names of my nieces.”* (Vann-Ward et al. 2017).

3.2.2. Coping with PD

Identity shift

To undertake a successful identity-shift, PwPD must preserve their previous inner-self to face the new life hopefully, but therefore, the new condition must be accepted (Hammarlund 2018; Lutz 2017):

“I want to be accepted even though I do have Parkinson's.” (P15, Hammarlund 2018).

Visible symptoms are easier to support in a private space, where PwPD feel confident, understood, and safe. Generally, PwPD are more comfortable, when they feel like their family still see their inner self, in the same way as before PD. They don't need to prove that they are still who they were before. But even with family and friends, a changed appearance may create barriers. A woman preferred to communicate via email rather than face to face, to hide PD to old friends that she had not seen for a while. Changing appearance influences PwPDs' representations about what others may think about them and lead to social distancing:

“That is not me...I don't want anyone to see me like that, because that is not who I am.”

(Vann-Ward et al. 2017).

Gender-feeling is disturbed by PD (Fleming 2003; Olsson et al. 2015). One woman explained that her body is still hers, but that she can't make it look or behave as she would like it to anymore. She feels *“misrepresented by her body”*, which impacts her sense of femininity (Bramley & Eatough 2005).

Hiding symptoms

PwPD have to be ready to expose their new identity with PD to others. They often try to hide symptoms, to avoid others to stare (Hammarlund 2018; Martin 2016). At the beginning of PD, PwPD hide symptoms to everybody: hands behind the back, under the table or the shaking hand in the other hand or in the pocket. A man was arrested in a store, because he was hiding his shaking hand in his trousers pocket and was accused of masturbating in public (Martin 2016).

“From time to time, people stare at me ... it's because of the tremors, but I try to hide it, I know how to do it, when it's too bad, I try to just hold on and hide it.” (P10, Valcarengi et al. 2017).

When hiding symptoms becomes too difficult, PwPD limit illness-related information, because they are afraid to lose respect and their status within their working environment (Bramley & Eatough 2005).

Occupational changes

When physical disability does not allow the execution of a chosen occupation, PwPD try to preserve, despite PD, the most important and meaningful activity which seems to characterize their being (Oehlberg 2008; Lutz 2017).

Regarding other occupations, as playing an instrument for instance, PwPD choose to preserve an activity which was the most important to them, and possible to maintain despite PD (Smith & Shaw 2016; Martin 2016). As did one woman, who loved playing the piano since her childhood. When she gave up her home because of PD, she preferred to maintain a place for her piano rather than keep more living space for herself (Lutz 2017).

Downwards comparisons

Downwards comparisons, such as imagining that one's child may have cancer or an accident, allow PwPD to put their condition into perspective and to forget what others may think about them (Hammarlund 2018).

Being optimistic

Even if PD is a daily challenge to actively find new solutions for new problems, a real illness conciliation and integration in daily life is possible (Smith & Shaw 2016; Oehlberg 2008). Participants underlined the importance of remembering positive things accomplished before PD, and of maintaining that positivity in the present (Hammarlund 2018; Oehlberg 2008; Vann-Ward et al. 2017):

“With Parkinson's you can still have fun. It's all in how you want to view it.” (Lutz 2017).

According to Gardenhire (2019), PwPD move through the following five phases toward optimism: (a) diagnosis, (b) initial reactions, (c) adjustment, (d) acceptance, and (e) living with optimism. Reframing optimism as a choice rather than a feeling, encourage to progress toward optimism. To preserve a daily life, as similar as possible to their previous one, PwPD are looking for complementary therapies (drugs or other strategies) to ease daily life with the new condition. In the absence of information given by the HCP, they try them secretly on their own, despite potential risks or adverse-effects, afraid to be judged by their physicians or families (Martin 2016; Sunvisson 2001):

“Nothing to lose, but some comfort in daily life to win.” (Low 2004).

4.2.3. The relationship with spouses

The Partner effect

Spouses caring for PwPD experience considerable stress and a feeling generating tensions, major frustrations, and ambivalent feelings, including some hostility towards their spouse on the one hand, and a feeling of helplessness and guilty for their attitude on the other hand. Most of them don't take any break to resource themselves and assist to an impoverishment of their couples' social network, due to reduced autonomy and stigma (Martin 2016; Chiong-Riveiro 2011).

But in healthy dyads, help is offered naturally in the right way for the PwPD (Martin 2016):

A husband saved his wife from an embarrassing situation during a conversation when she struggled to remember words and stopped talking suddenly; another one wanted his wife to go out once a week, to preserve a minimum of social life, so he systematically pretended that he forgot to buy a simple product, and his wife went to the store with him to do her own shopping.

An old man let his wife do everything (dressing, going to the letter box) even if he could do it himself, because he did not want to disturb her “*nursing*”. He became comfortable, and finally less able to look after himself.

Illness-induced role shift

Regarding gender related activities such as cooking and cleaning up the house, a role-shift is often observed (Martin 2016):

One woman remembers a humiliating situation. When she wasn’t able to clean up the house herself anymore, she saw her husband doing it for the first time, complaining he was doing this “*woman’s job.*”

Getting prepared and dressed in the morning may create a role-shift, which can only concern some moments of a day. One wife explains that she prepares and dresses her husband in the morning as a mother would do for her child, but after breakfast she shifts from her mother-role back to her normal wife-role.

The dilemma of accepting help or not

Spouses, children, other family members and friends are part of people’s intimate social life. They are the first to be concerned when help is needed. But PwPD only accept to receive help when they feel ready to (Lutz 2017):

“I’m too stubborn, too determined, maybe things change so you accept it, but right now, I’m not ready for that to happen.”

One man developed a system to put on his socks without any help to preserve independence, while another one experienced as a struggle hiring someone to perform electrical work, he would usually do himself:

“It’s a fight within me because part of me wants to be able to do these things forever, and the other part of me says maybe you shouldn’t do it.”

Accepting help can sometimes touch intimacy (Nijhof 1995; Solimeo 2008) and can be experienced as a dependence and compromise (Haahr et al. 2011). People, who were used helping others before PD, found it difficult to engage with individuals who were not a part of a close circle of friends or family. Accepting help from strangers or in public spaces threatens their identity as a helper to others (Lutz 2017). People expressed frequently the dilemma of accepting help or not and balanced between the need of independence and support (Lutz 2017; Hammarlund 2018): *“What really bothers me is that damn buzzer on the seat cushion. Every time I move, they (nursing aides) run here and tell me to stop and sit still. This is my apartment; I should be able to get up when I want to. If I fall, then they can help by picking me up.”* (Lutz 2017).

Others accept their partner’s help with difficult tasks at home, explaining that this was often helpful and not detrimental to their sense of self as an independent person (Lutz 2017), or that receiving help from a close, trusted person was both, comfortable and necessary to manage PD (Martin 2016).

PwPD may accept help in special situations, from selected people and for special needs. The kind of accepted help may vary from one day to another, from one situation to another and from one person to another. An exaggerated help leads to the PwPD’s overprotection and encourage the engaged loss of autonomy.

4.3 Mesocosmos

4.3.1. Daily life routine

Getting up in the morning is the first challenge of a new day with PD (Hammarlund 2018): *“I can barely find the strength to go to the bathroom, or brush my teeth, because nothing works.”*

(P1) Therefore PwPD sometimes prefer to take a shower rather than a bath.

“It takes a long time before you have finished dressing.” (P10)

Eating is not easy for PwPD: *“A I have a lot of difficulty to feed myself, I drop a lot of food on the floor because I shake a lot.”* (P21) (Valcarengi 2018).

Taking medication can be challenging regarding medication adherence on the long term (Gibson 2016). According to Shin et al. (2015), medication adherence is determined by medication responses, cost of medications, and forgetfulness. PwPD employ the following strategies to favor adherence to medication: seeking knowledge about medications, seeking advice from family and friends, use of devices, and use of reminders (Shin et al. 2015).

But even if medication is taken seriously, its efficiency and side-effects are diverse from one day to another or during a same day:

“If I take my pills and the expected effect doesn’t come as it should do, then I have to wait for the next round, and maybe not get any effect then either.” (Bramley & Eatough 2005).

Cooking can be difficult for PwPD and lead to involuntarily role shifts. One woman had to stop the cooking tasks. Her husband quickly found pleasure in his new role and did a good job. When his wife realized that she was losing her place as a housemistress, she decided to keep to herself her most successful recipes to preserve a piece of her pre-illness-identity.

Concerning travelling and car driving, to stop driving, because it becomes too difficult and dangerous for the PwPD or others, may mean losing independence and the possibility to

remain in social “face to face” contact, because driving does not only mean mobility to PwPD, but also independence.

“Now it’s not like the old days, when I used to be my own person, I had a car on hand and I went anywhere I wanted to. Now I depend on someone to go with me, I can’t go by myself, and this has affected me, it used to make me mad, but now I’m accustomed to it.” (P27) (Valcarengi et al. 2018).

Gardening is an appropriate meaningful activity to maintain body and mind. One woman discovered gardening (Lutz 2017):

“It was like my new life. I have to have something my own and to be able to do it myself.”

But gardening can favor falls. One man fell in his garden and was forbidden by his family to go on gardening, although he was not afraid to fall again and felt overprotected (Martin 2016).

4.3.2. Relationships with other people in a social context

The physical condition to be “*trapped in the body*” impacts concretely the dimension of space of daily life, because mobility is physically limited (Vann-Ward et al 2017; Lutz 2017; Fleming 2003):

“I mean, it’s simple, you are fixed in your flat.” (1/37) (Vann-Ward et al. 2017).

Everything changes when PwPD leave their private universe, which frightens many of them because they can experience stigma in society. Appearance in public space is a daily challenge because PwPD feel observed and judged (Bramley & Eatough 2005; Hammarlund 2018; Oehlberg 2008; Lutz 2017; Martin 2016). One woman was afraid to be judged by people who do not know her real inner self, imagining others would make misguided assumptions and see her as “*old and demented because of an age-related disease*”. When strangers in public places are staring, and even her own children who look at her in a different

way, her difficulty was, to show others her “*prior self*” which she knows is totally preserved: “*I am young at heart, that isn’t affected.*” (Bramley & Eatough 2005).

I’m ashamed of people saying I’m shaking. Sometimes, they don’t say it to my face, but behind my back, it gets me discouraged. (P14) (Hammarlund 2018).

Going to the restaurant is an enormous challenge: PwPD choose hidden tables to avoid other people’s looks and order dishes which are simple to eat, even when they would prefer something else: “*You can take me to a restaurant. If not too difficult things are being served, then I can have dinner with you as usual, without people thinking: what is that old man sitting there, sopping and messing around?*” (Hammarlund 2018). The feeling of shame is frequent and appears when PwPD feel that PD is triggering them to break social rules. PwPD perceive these difficulties as social incompetence. Involuntary movements in a restaurant or any other public space cause shame and fear of social judgement. Among them, there are for instance: as “spitting” during a conversation or being unable to get up quickly from a chair to shake hands (Nijhof 1995). Furthermore, a weak voice limits communication in a loud environment (Oehlberg 2008; Lutz 2017).

Assisting to social events can sometimes lead PwPD to show self-victimization in requesting unconditional and permanent help from spouses: A man forbid his wife to dance with others, because he wasn’t able to dance anymore and couldn’t stand to see her dancing without him (Martin 2016).

Regarding physical activity, PwPD tend to decrease their workload to cope with PD (Lutz 2017). Others give up their much-enjoyed sports when they realize that their condition may endanger themselves or others. This happened to a baseball trainer after an accident. His involuntary movement threw a ball too hard and hurt someone (Martin 2016).

Regarding the working environment as a challenge due to daily PD fluctuations, Mullin et al. (2017) determined two factors for workplace success for PwPD: ‘Feeling in control of Parkinson’s’ by actions to remain in control and ‘Being able to control Parkinson’s in the workplace’ by external factors supposed to positively influence their ability to work. Early-onset PwPD who are still working, often reorganize completely their “life-work-balance”.

“I was no longer the same, I could not perform the same tasks with the same speed, with the same energy, the pace was different.” (P19) (Valcarengi 2018).

4.4 Macrococosmos

4.4.1. Time management and uncertainty

The most important factors, imposing a reorganization of day-to-day life, are uncertainty and time-management (Martin 2016; Solimeo 2008; Barken 2014; Sperens et al. 2018; Shapira et al. 2017; Liao 2013). All dimensions of a person’s daily life experience are concerned by the experience of uncertainty due to the natural illness evolution. Uncertainty affects time-management and projects. On the one hand on a long-term point of view (what will my life be like in a few years?) and on the other hand on a short-term point of view (what will the next hour, or day be like?). PwPD experience uncertainty at different moment of their life course (Liao 2013). According to Ravenek (2017) and his study on young-onset PwPD, we can add the impact of uncertainty on their identities as young- and middle-aged adults within their socio-cultural context, deviating from the idealized age-graded life path marked which is associated to a feeling of loose of control over their lives and increased grief (Liao 2013; Ravenek et al. 2017).

Haahr et al. (2011) describe living with advanced PD as the experience of living, struggling, and managing unpredictability on a daily basis. In their study the following time related themes emerged: the body - setting the agenda, and always to struggle to be on time.

According to Hurt et al. (2017), carers experience uncertainty in parallel to PcPD, following the same five domain framework: symptoms and prognosis, medical management, self-management, social functioning and impact. Furthermore, carers experience uncertainty beyond exclusively illness-related issues.

Time is managed by a new daily life structure to optimize the life experience with PD. Daily life goes slower with PD but a day still has 24 hours, so that PwPD and families stop planning, trying to live each day as good as possible: “*Carpe diem!*” (Barken 2014; Sperens et al. 2018).

“You never know what tomorrow has in store, there are days like this, you’re able to do everything you had planned to, the other day, you can’t do anything, no matter how much you want to, times passes and you don’t do anything, and some days you’re awfully productive, you do everything you had planned to and the next day you can’t do anything[.]”

(P20) (Hammarlund 2018).

Past, present and future were the core categories that emerged in the study of Maffoni et al. (2019) while the *Past* is the dimension of regretted memories of past life before PD diagnosis, the *Present* is the dimension in which PwPD concretely experience the hindrances the resources associated with the condition, and the *Future* is characterized by both positive and negative visions of tomorrow. But according to Whitney, identifying markers of continuity encourages coping with PD over time so that older PwPD are able to maintain their quality of life (Whitney 2004).

5. Discussion

We tried to draw a realistic portrait of the daily experience of PD from the PwPD's and carers' perspective in order to identify concrete bio-psycho-social challenges and needs to meet by HCP involved in the global PD healthcare pathway. To synthesize daily life experience in a sociological framework of the daily life is interesting and pragmatic. In 2014, Soundy et al. (2014) conducted an important Meta-Ethnography of qualitative studies (n=37) about experience and perception of living with PD in order to generate their model of hope enablement. Soundy et al. (2014) identified five themes through their synthesis: 1) The effects of PD on an individual's social identity, 2) The psychosocial challenges an adjustment to PD, 3) Factors that influence the severity of the interruption on individuals' life with PD, 4) Cognitive, physical, and spiritual strategies and factors that influence an individual's well-being, and 5) social support and interactions that influenced well-being. To that exhaustive review, we can add 41 other studies, related to our research question. We confirm and underline their themes and found six studies in common. We will now present and discuss three existing social concepts and three new emerging concepts based on our findings in order to model our pragmatic approach of a Dynamic Daily Life Experience (DDLE) with evolving PD through a lifetime.

5.1 Existing social concepts

- *The theory of Prisoner of Parkinson* (Carlini 2017)
- *The five-stage theory of preserving self* (Vann-Ward et al. 2017)
- *Balancing within a web of needs on demands* (Hammarlund 2018)

The theory of "Prisoner of Parkinson"

That concept (Carlini 2017) describes a passive, (by spouses or providers), or active (by PwPD themselves) victimization process and can be reinforced and developed by our review.

PwPD can feel like “*prisoner of their own body and appearance*” (PD-mask as a uniform): “*Because of the stiffness of my face, people look at me.*” (Nijhof 1995). Furthermore, they become somehow “*prisoner of their medication*” because involuntary movements are regulated by treatments and the only way to keep some body control is to respect medication timing, which impacts the organization of daily life. The illness -imposed occupational changes can be compared to privation in prisons, such as limited choice of activity. To *release the prisoners of Parkinson*, Carlini (2017) suggests an interesting *physiotherapy of time-management* to reorganize daily life activities. As PD prevents PwPD from performing multiple activities simultaneously, daily volume of activities should be lightened to finish them correctly and satisfied. Therefore, doing less and simple activities, such as going for a walk with a partner, to discuss problems, solutions, desires, and new needs, helps to get some self-confidence and quality of life back.

The five-stage theory of preserving self

According to Vann-Ward et al. (2017), the theory of *preserving self* is comprised of five interdependent stages: 1) making sense of symptoms, 2) defining turning points, 3) experiencing identity dilemmas, 4) reconnecting the self, 5) envisioning a future. These stages are also observed in our review and can be considered as a mandatory step of the DDLE with PD. They can be used as a clinical guide to follow-up the illness-evolution and to support the process of *preserving self*, to avoid events like falls, or other risk-situations due to an overestimation of individual abilities.

Balancing within a web of needs and demands

According to Hammarlund et al. (2018) , the following four categories represent the impact of living with PD: 1) Changed prerequisites for managing day-to-day demands, 2) Loss of identity and dignity, 3) Compromised social participation, and 4) The use of practical and psychological strategies. Living with PD impacts the basic daily needs of control in

managing, control competence, relatedness, and autonomy which creates a shift from an internal to an external locus of control, which disturbs self-determination, leading to compensatory strategies or needs substitutes with negative consequences on health and well-being. PwPD try to balance that continuous shift between internal and external locus of control in order to maintain competence, relatedness and autonomy. Our findings confirm that concept, involving all the three space dimensions of our pragmatic approach.

5.2 Emerging theories of potential clinical utility

- *The PD-Partner effect*
- *The illness induced role-shift evolution*
- *The PD- Dilemma of accepting help or not*

The PD-Partner-effect

Loving spouses can help win the daily battle of a healthy mind against a sick body.

Spouses often shift from « *a lover to a nurse*», adopting an overprotecting attitude, especially from caring women to sick men, which maintains and worsens an ongoing process of active and passive victimization (Martin 2016; Solimeo 2008; Carlini 2017; Charmaz 1994). Daily disease experience is gendered and so are coping strategies. Symptoms are the same for both genders, but women and men do not suffer from the same ones. Women seem to be more embarrassed by thinking problems and on/off phenomena while men suffer more from the consequences of their appearance, affected by PD (Solimeo 2008). HCP must be aware of that phenomenon to offer person-centered care. Gendered coping strategies used by spouses, must be identified to optimize daily lived experience in a dyad. Women shift “*from a lover to a mother*” as they have a natural tendency to mother children and sick people (Charmaz 1994). Sick men easily accept this help, whereas men seem to have more barriers to accept the role-shift to care for their wives. Women try to overcome the daily problems on their own, trying to preserve independence for as long as possible (Carlini 2017).

Parsons defined the “sick role” as a process in time during which the individual is exempted from normal responsibilities (Parsons 1951) and Mc Namara & Durso (2003) found that spouses overestimate the PwPD’s suffering and can therefore accentuate an ongoing victimization process which could lead to more dependence, which this review confirms (Martin 2016 ; Solimeo 2008). HCP must take into account the partner effect and should include partners in shared care projects to improve the therapeutic alliance.

Illness induced role shift evolution

We observe an *illness induced role shift evolution* evolving in time, along with illness evolution, which may concern PwPD and/or spouses, but mostly the whole dyad.

Basic daily life activities in a dyad are often gendered (women cooking and men gardening). When PwPD can’t perform their gender related activity anymore, they are living (voluntarily or not) a *role-shift* (to redefine someone’s role in a dyad, in society and at work), which affects daily life experience in a dyad. Following illness-induced shift-evolution can be observed in our study: “*From a lover to a mother/father*” some moments a day and later all day long, to: “*From a lover to a brother/sister*” (sleeping separately, without contact), to “*From a lover to a nurse*” (providing pure nursing to the partner who lives his “sick role”). The additional “*carer-role*”, or “*nursing-role*” to fit in our theory, was also identified by Maffoni et al. (2019). The described process should be identified by HCP to preserve a healthy couple life. *Role-shift evolution* may indicate illness induced problems in the relationship and changes daily life needs for PwPD so that care projects must be adapted appropriately.

The PD-Dilemma of accepting help or not

A common and central theme linking all the dimensions of daily life with a chronic condition was help. Accepting help from a partner is not easy and PwPD must be prepared to it because

they may experience unexpected or undesired role-shifts. Spouses, caregivers and other HCP must consider the fact that the sick, sometimes uncontrolled body, might hide a preserved healthy prior inner self who won't accept any help. On the one hand PwPD regularly need help from others and on the other hand they want and must preserve their independence. Too much help can lead to overprotection and without any help, PwPD may experience dangerous situations. That concept reinforces the findings of Hammarlund et al. (2018) and their first category *Changed prerequisites for managing day-to-day demands* about the impact of living with PD.

5.3 Strengths and limitations

Strengths. The study is based on a big sample of PwPD's stories from 14 different countries which allows an interesting overview of their daily life needs with PD. Existing theories and concepts can be reinforced, and new theories emerge. The theory of illness induced role-shift-evolution was not yet described as a follow-up indicator to alert HCP in case of psychosocial disorders in natural illness evolution. The review promotes qualitative research in health to improve person-centered clinical practice. We suggest a pragmatic model of DDLE with PD and six simple questions to ask during consultations to explore the DDLE. Therefore, we could help HCP to be person-centered and to adapt care projects to the PwPD's personal needs.

Limitations. The PwPDs were not interviewed by the authors. Information about age and disease duration was inconstant. The used research methods and participant samples were very heterogeneous so that a meta-analysis was not possible.

6. Conclusions

Qualitative research allows HCP to understand peoples' daily life with PD. The perspective of their daily life condition must be explored to foster therapeutic alliance and to optimize person-centered care. The observed existing and new theories may be generalizable to other PwPD but also to other complex chronic conditions such as diabetes. The new pragmatic model of DDLE with PD can be used in primary and secondary care settings as follow-up indicator during illness evolution and encourage multidisciplinary holistic person-centered care. The partner effect must be considered for person-centered care projects to avoid or follow role-shift-evolution.

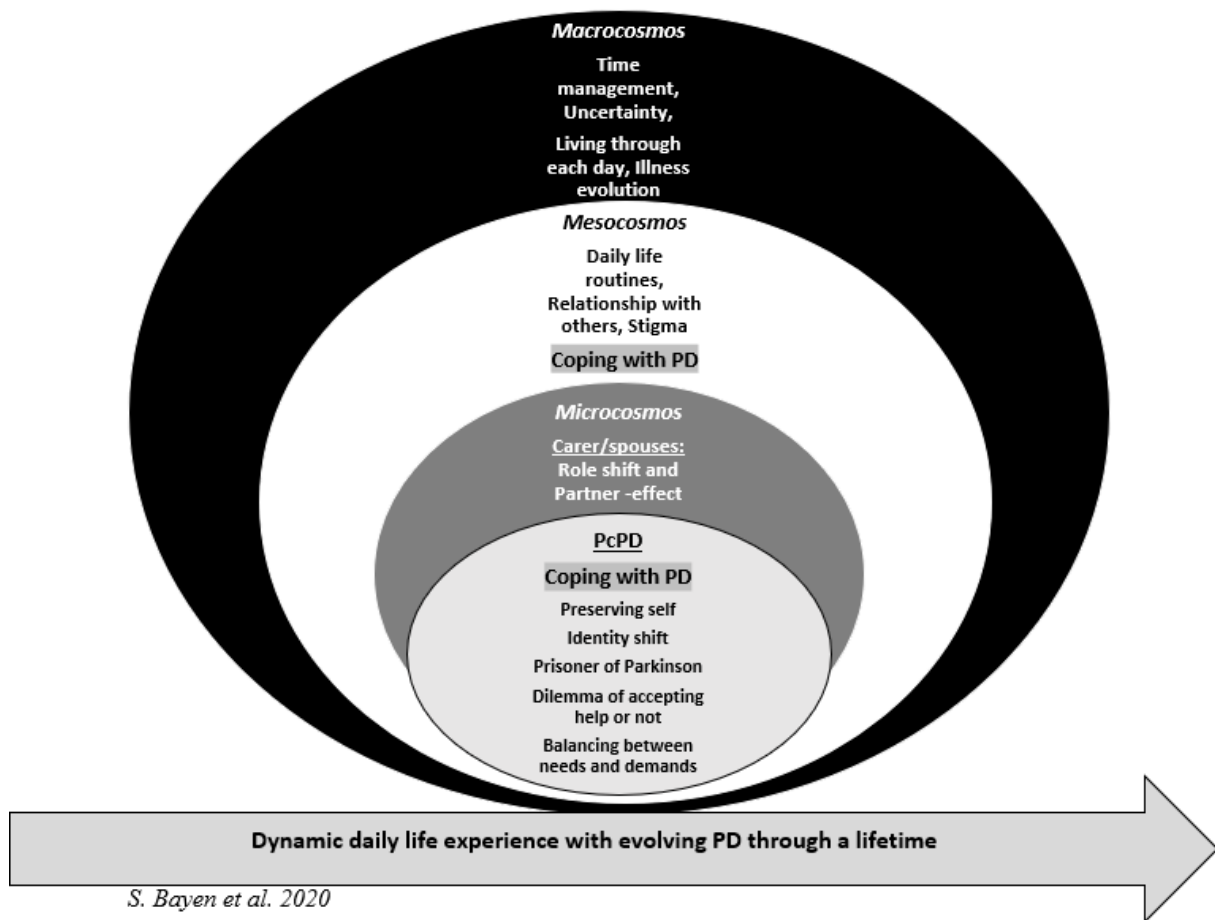
7. Relevance to clinical practice

HCP must be aware that peoples' priorities, in daily life experience with PD, are not always the same ones as for them (Shipper et al. 2014) and that they are evolving in time and space. Hammarlund et al. (2018) confirm that and suggests a shift from a biomedical to a needs-based approach. According to Kleiner-Fisman et al. (2013), coping with emotions, changing relationships, and social implications of PD is very important for PwPD in order to facilitate their new daily life.

HCP must therefore regularly assess the DDLE with PD which evolves in time and space.

We suggest here a pragmatic model of the bio-psycho-social DDLE with PD through a life course (Figure 2) to encourage and guide a person-centered discussion, including the individual, familial and social dimension to explore PwPD's daily needs and their evolution in time and space.

Figure 2: Pragmatic model of PwPD's dynamic daily life experience (DDLE) with PD in time



A person who discovers first symptoms of PD (motor-or non-motor) in a given moment during his or her life and after being diagnosed, will first try to *preserve his or her prior healthy self*. Simultaneously, an *identity shift* (to redefine new aspects of someone's identity) takes place to cope with the new condition, engaging the body (*Prisoner of Parkinson*) and emotions (*Dilemma of accepting help or not and balancing between needs and demands*) in space (*microcosmos: the PwPD with his or her inner self, more or less extended to spouses, generating Role-shifts and Partner effects, and mesocosmos: daily life routine in a wider social context, and macrocosmos: external, actively non influenceable threats*) and time (*short term: daily life and long term: lifetime*) and in a social context (*close: Role-shift (to*

redefine someone's role in a dyad, in society and at work) and *Partner-effect and distant relationships with other people*).

Occupational changes can indicate identity-, or role shifts

Identity-shift, according to Corbin and Strauss (1987), takes place in the PwPD's mind, following a chronological evolution: being someone before PD - getting diagnosed with PD- creating a new identity with PD - preserving the inner self before PD. It can be related to work, control, strength, sexual performance, and independence. It can be source of uncertainty regarding the loss of different aspects of a person's pre-illness identity, loss of self (Lutz 2017). Identity –shift is a process in time and PwPD must be ready to identify themselves, and to be identified by others, as a PwPD.

Daily life occupations are related to identity, which is formed and externalized by communication, self-presentation, and alter casting (Laliberte-Rudman 2002). Individuals aim to engage in occupations that contribute to a sense of identity that is both, acceptable and fulfilling to them (Sturkenboom et al. 2014). Abandonment of a basic daily life activity can therefore indicate a role-or identity-shift. Beyond physical possibilities, activities have to be meaningful to the PwPD and fit with their identity. To offer real person-centered care, HCP must consider that, when they suggest occupational therapies (Saint-Hilaire & Ellis 2013; Tracy 2002; Murdock et al. 2015).

For instance, to stop car driving, cooking, gardening, or other daily living activities can indicate a role shift, a partner effect, or a dilemma of accepting help. We must consider that, when, for the first time, a PwPD does not come to his consultation by car on his own. We further have to regularly assess their way to communicate because communication is also linked to identity (Tracy 2002) and can indicate identity shifts or even a risk of social isolation due to illness evolution.

PwPD expect HCP to pay attention on their authentic daily life situation with PD (Shipper et al 2014). To be person-centered and needs-based during a consultation, we suggest HCP to explore the PwPD's DDLE by six simple questions (Table 2) in addition to the PDQRS-39 (Hagell & Nilsson 2009).

Table 2: Questions to ask during consultations to explore the PwPD's DDLE

Question to ask during consultation	Explored dimensions of DDLE
<i>How did you come to the consultation today?</i>	Microcosmos: DoAH, PoP, BNaD, RS, PE
<i>Do you need help for your daily living activities?</i>	Microcosmos: DoAH, PoP, BNaD,RS,PE Mesocosmos: Stigma,Coping, Relationships
<i>Who is cleaning up your house, or repairing?</i>	Microcosmos: DoAH, PoP, BNaD,RS,PE Macrocosmos: IE, RSE
<i>Do you still have a meaningful occupation: gardening, sports, or playing an instrument?</i>	Microcosmos: Preserving self, IS Mesocosmos: Coping strategies
<i>How would you describe your relationship with your partner today?</i>	Microcosmos: Preserving self, IS, PE, RS Mesocosmos: Coping strategies, Stigma
<i>How do you communicate with others at home or outside?</i>	Microcosmos: Preserving self, IS, PoP, PE Mesocosmos: Coping strategies, stigma Macrocosmos:IE, Relationships with others

DoAH= Dilemma of Accepting Help, PoP=Prisoner of Parkinson, BNaD= Balancing Needs and Demands, RS=Role-shift, PE=Partner-effect, IE=Illness evolution, RSE= Role-shift evolution, IS= Identity-shift

Declaration of Interest statement

The author(s) declare(s) that there is no conflict of interest regarding the publication of this paper.

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Authorship

SB initiated this research. NM, MB, ZZ, and SB designed the study and conducted the systematic review. SB did the first draft. DD, CM, and LD reviewed the draft and discussed it with the other authors. All the authors agreed with the submitted version.

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Ethical statement

All procedures performed in the reviewed studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. As this literature review is retrospective, formal consent was not required and the participants' anonymity was guaranteed.

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