The lived experience of depression: a bottom-up review co-written by experts by experience and academics

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We provide here the first bottom-up review of the lived experience of depression, co-written by experts by experience and academics. First-person accounts within and outside the medical field were screened and discussed in collaborative workshops involving numerous individuals with lived experience of depression, family members and carers, representing a global network of organizations. The material was enriched by phenomenologically informed perspectives and shared with all collaborators in a cloud-based system. The subjective world of depression was characterized by an altered experience of emotions and body (feeling overwhelmed by negative emotions, unable to experience positive emotions, stuck in a heavy aching body drained of energy, detached from the mind, the body and the world); an altered experience of the self (losing sense of purpose and existential hope, mismatch between the past and the depressed self, feeling painfully incarcerated, losing control over one's thoughts, losing the capacity to act on the world; feeling numb, empty, non-existent, dead, and dreaming of death as a possible escape route); and an altered experience of time (experiencing an alteration of vital biorhythms, an overwhelming past, a stagnation of the present, and the impossibility of the future). The experience of depression in the social and cultural context was characterized by altered interpersonal experiences (struggling with communication, feeling loneliness and estrangement, perceiving stigma and stereotypes), and varied across different cultures, ethnic or racial minorities, and genders. The subjective perception of recovery varied (feeling contrasting attitudes towards recovery, recognizing recovery as a journey, recognizing one's vulnerability and the need for professional help), as did the experience of receiving pharmacotherapy, psychotherapy, and social as well as physical health interventions. These findings can inform clinical practice, research and education. This journey in the lived experience of depression can also help us to understand the nature of our own emotions and feelings, what is to believe in something, what is to hope, and what is to be a living human being.

Key words: Depression, lived experience, first-person accounts, experience of the self, experience of time, social and cultural context, recovery, pharmacotherapies, psychotherapies

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Depressive disorders are common worldwide, affecting 3.8% of the general population, i.e., about 280 million people[1,2]. As depressive disorders often have a young age of onset (peak: 20.5 years)[3], their associated health care and societal burden is enormous[4].

Over the past decade, several psychopathological investigations of the essential depressive phenomena have been published[5-10]. However, these top-down (i.e., from theory to lived experience) publications are limited by a narrow academic focus and a language that may blur the understanding of the lived experience. On the other hand, several reports written by affected individuals describe the subjective experience of depression[11-22], but these analyses are limited by fragmented, particular and contextual narratives that do not fully advance the broader understandability of the experience[23]. To our best knowledge, no studies have adopted a bottom-up approach (from the lived experience to theory), whereby a global network of experts by experience and academics are mutually engaged in co-writing a joint narrative. Co-writing is essentially based on sharing perspectives and meanings about the individual's suffering whilst maintaining each subject's diction and narrative style without formatting them in pre-established conceptual frameworks or narratives[23-25].

This paper is a bottom-up, co-written review of what is like to be depressed. We present a detailed account of depression by drawing on real-world lived experiences and first-person perspective narratives, enriched by phenomenological insights. Numerous individuals with a lived experience of depression across different age groups, genders, ethnic and cultural backgrounds, as well as family members and carers, were involved, along with academics. The adopted co-writing methods refined an earlier method developed by our group to investigate the lived experience of psychosis[23].

In the first step, we established a collaborative core writing team of experts by experience (patients, their families and carers) and academics (psychiatrists, psychologists, philosophers, and social researchers). This team conducted a comprehensive systematic search of Web of Science, PubMed and EBSCO, from inception until August 17, 2022. The search terms were: ("depressive disorder" OR "major depression" OR depress*) AND (qualitative OR "focus group" OR "grounded theory" OR interviews OR "content analysis" OR ethnograph* OR phenomenol* OR "in depth interview" OR hermeneut* OR autobiography OR biograph*) AND ("lived experience" OR "first person" OR "user experience" OR "patient experience" OR meaning OR beliefs OR narrative OR self-narrative OR "illness experience"). We included qualitative studies providing first-person accounts and involving adult participants (≥18 years), published in English, Spanish or Portuguese.

We focused specifically on experiences consistent with the DSM/ICD diagnostic criteria/requirements for unipolar depression, without committing to specific diagnostic subcategories, but excluding postpartum depression due to its distinct psychopathology and pathophysiology[26-28]. We did not focus on psychotic features of unipolar depression, as these were already discussed in our previous work[23]. The DSM/ICD diagnoses were ascertained by a clinical interview conducted by a health care professional, a validated diagnostic instrument (e.g., the Mini-International Neuropsychiatric Interview[29]), or a validated clinical scale with an established cut-off translating into a categorical diagnosis. Studies investigating depressive symptoms, self-reported depressive features, bereavement or "understandable sadness"[30,31] were not included, to avoid the confusion between these conditions and the categorical diagnosis of depression which permeates the existing literature[32,33]. Overall, our focus on ICD/DSM unipolar depression has broad clinical relevance without being so broad in scope to render the analytic task unfeasible[34]. Two researchers screened titles and abstracts, and discrepancies were resolved in consultation with a senior researcher.

In the second step, all included papers were uploaded to NVivo software[35] for qualitative data analysis. Four independent researchers conducted a thematic synthesis of selected sources based on line-by-line coding of the text in the Results/Findings sections of the papers and generation of a preliminary list of descriptive themes and sub-themes of the lived experience of depression. Further complementary sources, such as autobiographical books written by experts by experience, were included to better characterize the lived experience of depression reported outside the medical field (see Table 1). The material was then shared across the core writing team and preliminarily classified across three overarching descriptive themes: "the subjective world of depression", "the experience of depression in the social and cultural context", and "the lived experience of recovering from depression", each of which included several sub-themes. These themes and sub-themes hold narrative value only, and are not assumed to represent entirely distinct categories, but are interconnected and frequently cross-referenced. For example, while we sought to distinguish between mental and physical experiences of depression, first-person narratives do not clearly differentiate between the bodily and the mental domains.

Table 1 Selection of complementary sources considered for the review

Anto SG, Colucci E. *Free from pasung: a story of chaining and freedom in Indonesia told through painting, poetry and narration*[19]
Burnard P. *Sisyphus happy: the experience of depression*[16]
Brampton S. *Shoot the damn dog. A memoir of depression*[17]
Lott T. *The scent of dried roses*[18]
Merkin D. *This close to happy: a reckoning with depression*[11]
Plath S. *The bell jar*[12]
Scialabba G. *How to be depressed*[21]
Solomon A. *The noonday demon. An anatomy of depression*[13]
Styron W. *Darkness visible: a memoir of madness*[15]
Tolstoj L. *A confession*[22]
White LA. *When the world leaves you behind*[20]
Wolpert L. *Malignant sadness: the anatomy of depression*[14]

In the third step, we promoted a collaborative and iterative sharing and analysis of the preliminary experiential themes and subthemes in virtual workshops involving a wider global network of experts by experience and their carers from the Global Mental Health Peer Network (https://www.gmhpn.org), which represents lived experience from over 40 countries; the Young Person's Mental Health Advisory Group (https://www.kcl.ac.uk/research/ypmhag), representing the perspective of young people; and the South London and Maudsley NHS Recovery College (https://www.slamrecoverycollege.co.uk), representing the lived experience of recovering from depression. Overall, we involved about 20 experts by experience of different gender and ethnicity from four continents and 11 countries, encompassing Europe (Spain and the UK), North America (Canada), Asia (India and Indonesia), and Africa (Cameroon, Ethiopia, Ghana, Kenya, Nigeria and Uganda).

The themes and sub-themes identified in the previous steps were presented to this wider group of experts by experience to collect their feedback and enrich them with their subjective perspectives, in order to ensure global representation, particularly for low-middle income countries and ethnic, sexual or social minorities.

In the fourth and final step, the selection of experiential themes and sub-themes was enriched by phenomenologically informed perspectives[10,34,36]. The broader group of experts by experience and academics collectively interacted to draft and review the manuscript via a shared Google Drive platform. All experts by experience who actively participated in the manuscript elaboration were invited to be co-authors. They were offered reimbursement for their time adhering to available guidelines for participatory research[37].

In this study, the words written or spoken by experts by experience are reproduced verbatim in italics. Commentaries from experts by experience participating in our collaborative workshops are anonymized as personal communications. Notably, although this paper outlines the most paradigmatic ways in which depression expresses itself across the majority of experts by experience on a global scale, it is neither assumed that the experiences reported are exhaustive nor that they are systematically applicable to all indi-

viduals with depression. We rather sought to appraise the kaleidoscopic coloring and phenomenological heterogeneity of the lived experience of depression by acknowledging individual variability and complementary, if not contrasting, types.

THE SUBJECTIVE WORLD OF DEPRESSION

In this section, we describe the subjective experience of depression across three overarching narrative themes: a) the experience of emotions and the body, b) the experience of the self, and c) the experience of time.

Depression and the experience of emotions and the body

Feeling overwhelmed by negative emotions

The most typical experience in depression is struggling with overwhelmingly negative emotions, such as guilt and despair, fear, anger and boredom. Life is frequently experienced as dominated by a deep sense of unchanging and inescapable guilt because one cannot contemplate the prospect of positive change in one's life. Such irrevocable guilt shapes any other experience[7].

This feeling is deep, not directed at anything in particular (objectless)[38], and thus cannot be described in terms of feeling guilty about something[7,38]: "*One awful thing about my depression was the tremendous sense of guilt that I was unable to attach to any memory, or action or any part of myself*"[39].

In many cases of severe depression, the pervasive experience of guilt is accompanied by fears of inescapable illness, and takes the form of an all-enveloping and seemingly unavoidable existential worthlessness and despair[34]: "*I shall not exist. Then why go on making any effort? And how go on living?*"[22]. Individuals may fear the outside world, other people, their own emotions and actions, or the future: "*I had a fear of change, fear of dying, fear of failure, fear of success, fear of being alone, which paralyzed me for years and years*"[40].

The interpersonal world is perceived as threatening, offering only suffering and disappointment: "*I am afraid of having relations with others, but I was not like this before*"[41]. Bonding with others may also be hampered by significant irritability[42], which impedes closeness: "*I get angry. I just hate noise. It disturbs and destroys me and I find myself arguing with others*"[41]. Familiar people can also be perceived as boring and unimportant, or as additional burdens: "*I just cannot deal with hearing all your troubles today. I've got enough to deal with on my own, just trying to keep myself afloat*"[43].

Feeling unable to experience positive emotions

In depression, positive emotions are overshadowed by negative ones. Individuals describe the inability to recognize and experience positive emotions such as pleasure: "*I tried to lick the honey which formerly consoled me, but the honey no longer gave me pleasure*"[22]. They also feel unable to experience happiness ("*I have of late lost all my mirth*"[34,44]), love ("*My husband expects me to express my love for him, but I do not know where I can find this love")*[45], or affection towards others ("*Because I was depressed last year, I became absorbed in my own self. I didn't care about others", personal communication).*

In the extreme variant, individuals may find it difficult to experience any emotions at all ("feeling of the loss of feelings"[46]). This experience leads to detachment from others and the world, coupled with emotional anesthesia and inability to establish relationships with others: "*A loss of feeling, a numbness, had infected all my human relations. I didn't care about love, my work, family, friends… or physical/emotional intimacy… I was losing myself, and that scared me*"[13].

Feeling stuck in a heavy aching body drained of energy

Individuals with depression frequently report low levels of vital energy: "*My vital energy is depleted*"[47]. This loss of energy, the driving force that pushes us to get involved in the world and directs our lives[48], can lead to a sense of exhaustion, or even paralysis: "*I am tired in the morning and tired at night and tired all day and never, never feel fresh*"[49]. People with depression tend to experience fatigue even when faced with mundane daily tasks involving bodily movement: "*Like you're swimming against a sea of something coming at you*"[50].

The body is so heavy that it impedes any movement: "*For me, it feels like gravity just starts working on my body harder than it works everywhere else in the world*"[51]. Physical heaviness is described as an intense sensation of oppression: "*It's like a pressure on my body, a pressure on my head*"[52], often associated with bodily pain: "*I get sort of like really sensitive… it's just pain that goes on and on*"[53]. Bodily pressure or pain can become so unbearable as to trigger extreme somatic delusions[54,55], such as the conviction that one's body is no longer functioning: "*I can't eat or drink because the bowel is blocked*"[56].

Feeling detached from the mind, the body and the world

Individuals living with depression often report experiences of detachment from their own mind, the body and the outside world. They also describe a reduced sense of both agency (experience of initiating and controlling) and ownership (feeling of mineness)[57] of thoughts, emotions, behaviors and bodily processes, which continue to occur on their own, leading to feelings of disconnectedness: "*I'm not in my body, I'm not in my mind, I'm just totally disconnected from myself*"[53]. While the body ordinarily operates as a medium through which the world is experienced, it becomes now uncomfortably alien and obtrusive, like an object external to oneself[58], working on its own and automatically: "*I do everything automatically, the signals from my body are shut down, I don't listen, I become like a machine, just doing what needs to be done*"[49].

Feelings of bodily detachment are often accompanied by a sense of distance and disconnectedness from the surrounding world, including others[5]: "*There was no real connection. You feel like you're*

talking and doing everything you should, but you're not really there. It's like you're removed from yourself… You weren't really connecting with other people"[43]. The surrounding world also appears immersed in an atmosphere of artificiality and unfamiliarity, devoid of its more usual emotional tone: "*I felt like in an artificial world that I didn't recognize*"[49].

Feelings of artificiality can become so pervasive to lead to depersonalization and derealization, characterized by the loss of bodily vitality and disconnectedness from the world. These experiences corrode the ordinary and "pre-reflective" (i.e., unconscious) sense of "belonging to a shared world"[34], which characterizes the human experience. The resulting overarching experience is a deep sense of estrangement and exclusion, which can lead to the struggling feeling of being cut off from an interpersonal world of possibilities that others continue to inhabit[34,59]: "*I feel completely cut off from the rest of humanity, the rest of the world, the rest of existence. I am a walking corpse*"[60]. This dramatic feeling of a lost world of possibilities can be experienced as the confirmation of one's inhumanity, further amplifying ruminations of guilt or even self-hate: "*I am not human… I hate myself*"[60].

Depression and the experience of the self

Losing sense of purpose and existential hope

A typical experience reported by people living with depression is that life has lost its purpose. This feeling is unchanging and irrevocable: "*All I seemed to be able to do was exist in the moment with no drive or purpose, no reason for being*"[20]. Individuals report existential despair, a loss not merely of many hopes but of the so-called "ground for hope"[61], the ability to hope for anything: "*Today or tomorrow sickness and death will come to those I love or to me; nothing will remain but stench and worms*"[22].

Individuals who despair withdraw from active involvement in the world: "*[Depression] comes with a loss of being fully engaged in the world around you*" *(personal communication)*. The drive of agency and motivation collapses[62]: "*I felt like my life was changed upside-down… I had become still and then driven down. I felt like nothing was important*"[63]. The outer world loses its importance, and the inner life becomes dominant, thus weakening the sense of practical connection with the world: "*At first you can still kind of function in the world – but then… you start living in your own mind*"[51].

Still, the person might feel an urgent and pressing need to act upon one's situation, to bring about some transformation. In a world deprived of meaningful change, the result is often a directionless psychomotor agitation ("*I just wandered, and wandered and wandered. Went about like a dog in a cage… I couldn't sit and eat… It was like a motor inside that you have no control of*"[64]), experienced both in the body and the mind[34].

Mismatch between the past and the depressed self

People with depression feel unable to recognize their usual self, feeling awkward: "*I guess I felt strange and alien*"[43]. They frequently describe the experience of not matching one's past self: "*I don't even know myself anymore*"[65]; "*I was losing… any sense of who I was*"[20]. Individuals struggle to recognize themselves as the person they used to be: "*I don't recognize, and I don't like the person I've become… It's almost like a slow erosion of the spirit*"[66]. This may amplify feelings of hopelessness, loss of purpose and lack of self-worth. Individuals may experience a self-alienation, observing themselves and their behavior from the outside as not fitting: "*You look in the mirror, and you still look the same, but you feel like you should be looking different. You feel like you've just gone*"[66].

Often the mismatch between the old and the depressed self is not noticed by others, leading to further isolation and incomprehension: "*Everybody else still thinks that this is me. But the person I knew myself to be, is gone. Just went away*"[49]. In this context, the past self is frequently idealized and desired in the face of the impotence of the depressed present self: "*I remember when I had a spark, high energy and the ability to motivate others. I desperately want that back*"[66]. However, it is also possible that people with depression are not able to relate to the past self: "*In my depression [the past self] disappeared, it was like it had never been that way… I could not relate to how I had been*" *(personal communication)*.

Feeling painfully incarcerated

Many people suffering from depression describe it as a prison they cannot escape: "*Depression is like a hole. You are stuck in the hole. You can't get out*" *(personal communication)*. The metaphors used (e.g., a hole, a fog, an endless tunnel) equally express the sense of violent constraint and impotence: "*Lost in a really thick fog, you can't find your way out, you have no direction or energy. It weighs you down, and you can't work it out*"[67]. The poet S. Plath metaphorized her depression as a bell jar: "*Wherever I sat – on the deck of a ship or at a street café in Paris or Bangkok – I would be sitting under the same glass bell jar, stewing in my own sour air*"[12].

The subjective feeling of incarceration is frequently described through physical symptoms, such as shortness of breath, feeling of suffocation, and fatigue, in particular in some cultural contexts: "*Living with depression is like walking in a dark tunnel with no end to… feelings of suffocation and shortness of breath*"[51]. The heavy, aching body is perceived so uncomfortably to become a prison itself: "*You feel like you are a prisoner in your own head*"[51]. To cope with this tension, individuals with depression unsuccessfully attempt to fight the feeling of oppression or passively accept being imprisoned: "*You give your power away, become immobilized and can't move through it*"[67].

Losing control over one's thoughts

People with depression often report the subjective experience of not being able to think or concentrate. They may perceive their thoughts as confusing and unclear, as if they were shrouded in fog: "*It's like a funky fogginess… I can't think, I can't concentrate. My*

words end up not even coming out the way that they should"[40]. A state of mental congestion is frequently experienced: "*Just hundreds of thoughts whirling around in my head, with no function or order. It's complete chaos*"[34].

The feeling of not being able to control one's thoughts may translate into the loss of agency with one's inner life. For example, people may feel at the mercy of ruminations of depressive thoughts: "*The thoughts just come… Sometimes I don't want to think but the thoughts just come. I try to stop them, but I can't*"[63]. Depressive ruminations typically focus on guilt, inadequacy or worry, and it is not possible to divert them, as if they had a life of their own. People feel overwhelmed because they don't have the strength to contain these negative thoughts and the anguish they cause: "*I'm trying to change the subject, but my brain is telling me to worry about this, worry about that, and the next thing, I couldn't concentrate on anything else except what was in my head*"[43].

Losing the capacity to act on the world

Based on the experiences described above, people living with depression may feel that they have lost the ability to act in effective or practically meaningful ways: "*I felt totally out of control, and there was no way to gain control, to take control of my life, or at least to have control of some of the events*"[52]. Even the simplest undemanding and ordinary daily activities and duties are perceived as an insurmountable difficulty[14]: "*You go to the wardrobe, and you look at your blouses, and you stand there in a state of indecision for ages before you can decide whether you'll wear the green one or the white one. Everything seems to assume momentous importance*"[68].

Depressed individuals may feel powerless and frustratingly unable to predict whether the next day they will be able to carry out ordinary tasks and therefore act on their life, feeling totally at the mercy of their mood: "*I never know whether I'm gonna be able to do what I planned that day until I get up that morning… Like I never have any control of my life*"[66].

Individuals with depression frequently describe indecisiveness, which impairs their ability to act on the world: "*I cannot decide even about the simplest things. Whenever I make a decision, I fail to do it*"[41]. Indecisiveness is closely associated with the sense of lacking immersion in the world: "*Every decision was segmented into a thousand tiny decisions. It came with a loss of being fully engaged in the world around you*" *(personal communication)*.

Feeling numb, empty, non-existent, dead

One of the most extreme experiences sometimes reported by people with depression is the loss of vitality of the self. The self is experienced as numb, empty, non-existent, as a walking shadow[69], or even dead[70-72]: "*I was feeling numb. All the things that used to make me happy felt like nothing*"[19]. An absence of thoughts and emotions is also described: "*You're just blank, there is no you, you just exist, you don't live… There are no emotions, no thoughts, no nothing… It's a state of numbness*"[53]. The feeling of emptiness is so strong as to be disabling, bringing with it an inability to properly function in the world: "*All of me got empty; my head, my body and the whole world*"[49].

The sense of numbness and emptiness leads people to conclude that they do not exist at all: "*I don't even exist anymore*"[69]. The givenness of being alive and existing, far from an immediate and pre-reflective certainty, becomes utterly doubtful and must be continuously and practically verified: "*My head is empty, so I keep marching about to know I'm alive*"[56]. In their most pronounced form, these experiences can amount to a feeling of total annihilation of the self; people describe having become like nothing, as if they have disappeared and died[69]: "*I feel dead. And [I have an] inarguable belief that I am nothing*"[60]. The feeling of non-existing and being dead can extend to the surrounding environment and even the world, whose existence is doubted: "*It feels like there's nothing outside of here*"[29]. The non-existence of one's own body and world may be firmly believed with delusional intensity (known as Cotard's syndrome)[73].

Dreaming of death as a possible escape route

Living with the experiences described above amounts to insurmountable mental and bodily pain and suffering, which the feeling of being emotionally dead cannot even alleviate: "*I feel dead. And yet, being 'dead' doesn't relieve the overwhelming, insurmountable pain inside me*"[60]. Therefore, people with depression often perceive their lives as meaningless and imagine death as the only way out of their existential pain and despair[34]. Death appears as an escape, given the lack of purpose for living and the impossibility of alternatives in the future: "*The only end I see for me is death really, quite honestly*"[53].

Suicide may be felt as the only possible escape from the apparent perspective of eternal incarceration and suffering[11]: "*Anyway, I felt that I must die… Everything would be over if I died. There would be no memory, painful memory, and no more real-world pressure. I felt that death could solve any problem*"[19]. Contemplating suicide may be experienced as a personal relief[17] as well as a relief for the loved ones: "*Now I think death is the best option for me… My death might hurt my family for a few hours, but now I hurt them every minute… Death is easier for me*"[17].

Depression and the experience of time

Experiencing an alteration of vital biorhythms

A common experience is the disruption of vital biorhythms that regulate one's daily life, affecting the basic biological functions of sleep-wake, hunger, and sex drive: "*I had sleep problems… I had poor appetite. I was constipated… I also had back pain and sexual problems*"[41]. Altered biorhythms in depression represent a disruption of the basic (pre-reflective) attunement between soma and psyche, and between the person and environment[74]. Biorhythms can be de-synchronized ("*I can't get to sleep, I lie awake and doze off a bit, sweating, chaotic*"[75]); inverted (*"My body just wanted to sleep. I would often sleep 20 or 22 hours a day", personal commu-*

nication); or flattened ("*I found myself eating only for subsistence: food, like everything else within the scope of sensation, was utterly without savor*"[15]). Sleep abnormalities are particularly perceived as disturbing. Despite feeling exhausted, individuals are often unable to conciliate a restorative sleep: "*Most distressing of all the instinctual disruptions was that of sleep… Exhaustion combined with sleeplessness is a rare torture*"[15].

Experiencing an overwhelming past

Depression stops the orientation and movement of life towards the future, which gives meaning to life[69], and ties affected individuals to the past[38], unable to move beyond its overwhelming grappling force and weight: "*I can't get away from my experience in the past*"[60]. The past becomes predominant, invading and erasing the possibilities of the present and the future[69,76,77].

Given that the world is devoid of future positive possibilities and changes, the significance of past events is no longer amenable to reinterpretation in the light of present events. The experience of the past is irrevocably fixed and determined once and for all[69]. Actions made in the past become irrevocable faults that cannot be expiated ("*You get what you deserve in life. And I don't deserve nothing*"[50]) or forgotten ("*I feel I am suffering more than a murderer is suffering. In the end, a murderer forgets, and everything goes away from him*"[7,39]).

Past faults thus reverberate in the present as guilt, shame and regret: "*Guilt about past life suffocates me*"[56]. As past faults cannot be changed, people feel that they deserve punishment and anticipate condemnation: "*I have to be punished for past misdeeds*"[56]. Depression itself could be subjectively perceived as a much-deserved punishment for past faults, potentially leading to self-harm behaviors.

Experiencing a stagnation of the present

Faced with the tyrannic dominance of the past, the present time in depression is subjectively perceived as suspended, totally stagnating: in the landscape of futility, nothing has significance, and everything just passes[69]. People with depression do not perceive the normal flow of time, which appears slowed down or stopped: "*I can't remember days because time has stopped*"[56]. The present drags on to what seems like an eternity in a world devoid of practically meaningful possibilities, where nothing new of significance occurs: "*Time seemed an eternity*"[56]. This lost sense of becoming leads to feelings of boredom, meaninglessness and worthlessness.

Sometimes, people feel that the world is coming to a complete stand-still: "*I look out of the window of my hospital room, it looks so overcast outside, the birds have stopped singing, the flowers blackened, silence, everything has stopped*" *(personal communication)*.

Experiencing the impossibility of the future

As time leads nowhere, several depressed individuals experience the future as an empty space which is no longer offering possibilities for positive changes: "*It just feels as though there's a big hole in the future, there's a big empty space somewhere that I'm going into, and there's just nothing in it*"[53]. The future contains nothing but never-ending pain and suffering: "*It was like existing in the dark, expecting a future in darkness as well*"[78]. The future can also be experienced as a mere repetition of the past[21] or an endless continuation of the dark present: "*The future was hopeless. I was convinced that I would never work again or recover*"[14].

The genuine possibility of an open future is negated, and several people with depression experience the impossibility of any future change or improvement[62], with a profound loss of hope and of all possible personal directions: "*I'm just dreading the future. There is nothing I look forward to, there is nothing… and I don't see it getting any better*"[53]. Some people describe the future itself as taking the form of an all-enveloping threat, more specifically, the threat of condemnation by others. This sometimes relates to guilt – all that one anticipates is punishment, something nasty is coming, and one awaits judgment[34]. Because of the impossibility of future positive change, depression is experienced as an eternal incarceration[69]: "*One thing about depression is that it feels like it's gonna go on forever… it's never gonna end*"[45]. And, if nothing can change, there is no escape other than death[34].

THE EXPERIENCE OF DEPRESSION IN THE SOCIAL AND CULTURAL CONTEXT

In this section, we explore the lived experience of depression across two overarching narrative themes: a) the experience of depression across different cultures, in ethnic and racial minorities, and across genders, and b) the interpersonal experience of depression.

The experience of depression across different cultures, in ethnic and racial minorities, and across genders

Experiencing depression across different cultures

The subjective experience of depression is deeply influenced by other people and by sociocultural contexts characterized by specific norms and values. For example, the biomedical model, which predominates in Western societies, posits that depression is primarily an "inner" and individual mood disorder[5]. This model is not universally accepted[79-81], coexisting and conflicting with other models of depression (e.g., religious), in particular (but not exclusively) in low- and middle-income countries: "*I've seen a psychiatrist and a bomoh [traditional Malay medicine practitioner]. I knew it was not right to see bomoh, but I do believe the bomoh will help me strengthen my faith… I do believe the power of will inside me will help me against my illness*"[60].

In these cultures, individuals may perceive depression as a "rich people problem": "*It's something that only white people have*" *(personal communication)*. The mental suffering of depression can be

experienced as personal incapacity and laziness, and "emotional needs" are considered much less important compared to the "basic material needs": *"I'm fine… I just feel sad, and I've a reason to be sad… Nothing to do with hypertension, cancer or heart attack… it is only a sad feeling, which occurs from my heart"*[60].

The lack of medical recognition of depression can lead to the belief that it is an experience that one should manage oneself, implying that individuals are responsible for their disorder[82-84]: "*It is not an illness… Depression is cured by oneself putting forth effort*"[85]. For example, among Australian First Nations, depression is primarily experienced as weakness or injury by spirits[86], which is not thought to require medical care: "*The [spirits] can cause you to be really sad or withdrawn or angry, or they can make you physically ill, like me, and then the doctors won't be able to find a cure for you*"[87].

In cultures whose members do not experience themselves as much as separate individuals but rather as parts of a social community, depression may be conceived not as an intra-psychic but rather as a bodily, interpersonal or even "atmospheric" process[5]. Bodily experiences of depression are themselves shaped by cultural variables, with "nerves" and "headaches" often featuring in Latino and Mediterranean cultures; "imbalance", "weakness" and "tiredness" in Chinese and Asian cultures; and "problems with the heart" in Middle Eastern cultures[34,88].

Experiencing depression in ethnic and racial minorities

Cultural differences in the experiences of depression are also a significant challenge for ethnic and racial minorities. Their suffering can be exacerbated by a mistrust of health care professionals because of a lack of reciprocal understanding: "*What do they understand about our ways? I wouldn't tell them – they would laugh at us and think we were strange, so I don't tell them" (South Asian in the UK)*[87]. Such mistrust is sometimes aggravated by perceived racist and discriminatory attitudes by health care workers: "*[Health care workers] are just more cold, like emotionally something happened to you that's traumatic, they're very cold" (African American in the US)*[89].

This feeling of not belonging to the main social group exacerbates a sense of isolation and difference that is already prominent in depression[90] and adds to the emotional burden: "*My depression might not be like Suzie Ann's depression?… They're going to treat her just a little bit more different than me" (African American in the US)*[89]. Discriminatory experiences of depression are also described: "*I'm part of an ethnic minority group in Indonesia, so there are systemic discriminations… there's a sense of mistrust" (personal communication).*

Experiencing depression across genders

While both male and female individuals with depression commonly report feelings of diminished self-worth ("*I've lost all my confidence*"[91]; "*The weakness within me has come out*"[63]), such feelings are differently tuned according to gender-specific stereotypes.

Male individuals tend to struggle with masculine stereotypes concerning a perceived need to be in control, successful, self-reliant, and not to show signs of weakness[18,52,92,93]: "*I think you grow up with it – men don't cry… it's the social group that does it… 'don't be a sissy'*"[94]. They often experience more difficulty expressing their emotional feelings and thoughts about their depressive disorder[41,95]: "*You have to be as macho as possible… perhaps makes it hard to express your feelings verbally*"[92].

On the other hand, women tend to be subjected to feminine stereotypes concerning emotions ("*I think girls more often, just like me, worry about a lot of things*"[6]) or motherhood ("*My kids are lonely… I have not taken care of their food or clothes in the past four years. I feel guilty*"[41]; "*a mother who is too much shade and too little sun*"[11]).

The interpersonal experience of depression

Struggling with communication

Individuals living with depression experience a profoundly altered world characterized by a deep loss of interpersonal connection, which is not shared and understood by others: "*[Depression] remains nearly incomprehensible to those who have not experienced it in its extreme mode*"[15]. Conveying and communicating such an all-enveloping alien reality becomes particularly problematic[34]: "*I'm hurting so badly, I don't even have the words to describe it… I'm a person of words, of descriptions, of communication. Now, I feel stripped of even that one small comfort: being able to express how I feel*"[60].

Individuals may feel alienated from others and unable to relate to them[34,96]. Isolation is exacerbated by the loss of physical connection that otherwise mediates the non-verbal communication of feelings and intentions. This deep communicative obstacle augments personal suffering by impeding interpersonal comprehension with family members and friends: "*I have had a hard time describing what it feels like to people. Especially when someone asks you what's wrong. You know what's bothering you, but you don't know what to tell*"[51].

In the attempt to re-establish meaningful communication, people may resort to metaphors, which help to mentalize and consequently communicate what would otherwise be difficult or impossible to express with non-figurative words[97]. The metaphors often describe restricted movements ("*I could not move; even picking up a cup required a serious attempt*"[41]); feelings of being in front of "*a wall*"[98] or finding oneself in "*the bottom of a pit*"[98] or "*in a dark place*"[98]; or an impaired perception of the environment or the self with ineffable feelings of isolation and hopelessness ("*The sun would shine, but it would be dark. So, I couldn't feel the sun; it really shines and brightens every day, but I couldn't feel the sun. As much as I could feel the rays hitting my body, I couldn't feel it. It was very deep, deep darkness. The light could not penetrate through", personal communication).*

Feeling loneliness and estrangement

Feelings of social and personal isolation, not being understood by others, and being cut off from the world, play a central role in the subjective experience of depression[34]. Interaction with other people becomes uncomfortable[99] ("*Part of what people say is upsetting, so I stay away from them*"[45]), meaningless ("*I feel like what people talk about is trivial and irrelevant*"[43]), or outright hurtful ("*The act of socializing seems like an act of self-harm, to expose myself to get hurt*", *personal communication*). The poet S. Plath, who struggled with depression, points out the emotional burden of being expected to keep up appearances: "*I also hate people to ask cheerfully how you are when they know you're feeling like hell and expect you to say 'fine'*"[12].

Lack of trust or, at times, an explicit sense of being unsafe or threatened by others are recurrent experiences that complicate interpersonal relations: "*I'm like a focus of attack, you know, it feels like all around me, you know*"[53]. This lack of trust is often accompanied by jealousy, resentment[43,75,100] and even paranoid interpretations: "*When people are talking to each other, I think they are talking about me*"[41].

Withdrawing from other people can be experienced as a relief from social pressure: "*Isolation can help me. That was my 'go-to' place*" (*personal communication*). Avoiding interaction allows the person to escape the otherwise unavoidable complications of interpersonal relationships: "*Living alone is fabulous. When you live on your own, you can get away from it all*"[101].

Although social isolation can function as a way of erecting a protective shield against other people ("*You just want to hide away from everything, that's all*"[68]), it is paradoxically also felt as extreme loneliness, generating a desperate cry for human contact: "*Why do I want to live in the world? Nobody loves me. None!*"[102]. This deep disconnection from others creates an agonizing longing towards intimacy and social relationships: "*I miss the interdependence in marriage and at work; when you lose that, everything falls apart*"[103].

Perceiving stigma and stereotypes

A deeply troubling dimension of depression is the pervasive experience of stigmatization, often eliciting internalized feelings of shame, guilt, and being worthless or weak[78,100,104] ("*Public stigma is internalized into the self-stigma… that we are lazy, worthless*", *personal communication)* or of being somewhat less capable than other people ("*Telling people is sort of showing your weakness, your underside, and they'll think less of you because you're weak and you can't cope with life*"[94]).

Hiding one's suffering is a common way of not having to deal with stigma: "*It's like there are two different yous*"[43]. It can be a strenuous task to constantly hide one's pain behind a surplus of energy or a mask of joy: "*I've always managed to put on this happy face*"[51]; "*I could no longer go to work, pretend to be well, and maintain a brave façade of happiness only to arrive home in tears*"[20].

Hurtful stereotypes often worsen the experience of suffering ("*People think you are making yourself out as the victim, or you are being silly… that it is just me wanting to feel bad*"[85]), or lack of understanding from the family ("*My parents still don't think that I'm sick*"[105]; "*I was not ready to accept the stigma of being called crazy by my own family*"[19]). Unhelpful comments such as "*Can't you just choose to be happy?*"[51] or "*Oh, we all get sad*"[94] are experienced as damaging because they turn the disorder into "*something that does not exist, something that you cause yourself*"[85]. Stigma and stereotypes can amplify the suffering by implying that the person is somehow responsible for the depressive disorder.

THE LIVED EXPERIENCE OF RECOVERING FROM DEPRESSION

In this section, we describe the lived experience of recovering from depression across four overarching narrative themes: a) the subjective nature of recovery in depression, b) the experience of receiving pharmacological treatments, c) the experience of receiving psychotherapy, and d) the experience of receiving social and physical health interventions.

The subjective nature of recovery in depression

Feeling contrasting attitudes towards recovery

Individuals often describe contrasting experiences of recovery from depression, reflecting an ambivalent attitude concerning different components of the process. Even the very meaning of "recovery" can be variably understood as the simple disappearance of symptoms, as a return to "who I was", as the future starting to open up, as a profound existential maturation, or as a middle ground between these experiences. As the healing processes seem to involve something unpredictable, some patients may prefer to speak about "discovery" rather than "recovery": "*I think rather than the word 'recovery', it's more 'discovery'… it's a journey of discovery that does not necessarily have an end*" *(personal communication)*.

The recovery process implies acknowledging that depression is not simply a disorder in the biomedical sense but, more broadly, a human experience[106-108], although not an unavoidable aspect of all human lives. The human experience of depression is a different way of being in the world, a different life-world experience[109]. Thus, the life-world experience of depression may also include an existential change in a positive sense: "*What has changed? I think my outlook on life, I love life, I really do*"[110].

By some individuals, recovery is described as restoring personal stability and functioning: "*I really have to put so much effort to stay stable, to function normally*"[111]. However, rather than accepting that one is somehow stuck with depression for life, recovery has to do with regaining a sense of at least partial agency of one's existence and a renewed appreciation of life[74]. Changes and possibilities reappear after having been out of reach for a long time.

This rediscovery of well-being does not imply a denial of depression, but a greater awareness of one's own limits: "*It gives me hope that you can still have life even though you have to change it around a little bit*"[105].

Recognizing recovery as a journey

Most individuals describe recovering from depression as a journey; one goes through something horrible to reach a peaceful destination, a condition of enhanced strength. This is achieved through self-understanding, often involving a change of perspective regarding oneself and, therefore, personal growth, accepting that sometimes healing depends upon factors outside one's control (e.g., medications and other people): "*Many times, I have said coping with depression enriched me… I live a more conscious and a grateful life*"[112].

On the other hand, recovery is not always experienced as a process of personal growth. Some people are so distressed that they just want to erase the illness from their memory and return to their lives and past selves as if nothing had happened: "*Doctor, when will I become my old self again?*" *(personal communication)*. The idealization of the experience of depression and of recovering from it can even be criticized: "*There is, for me, little to be 'learned' from being depressed. It is certainly not a spiritual journey or one that is likely to lead to 'finding oneself'*"[16].

Actually, the trajectory of the journey is seldom so neat, and its endpoint seldom so clear: "*Recovery is not a straight-line process, there will be a lot of ups and down. It's a long way process. It's a life learning*" *(personal communication)*. Furthermore, the process of recovery can be experienced very differently by the same individual in different moments – it is not a black-or-white crystallized picture: "*It's more of a cyclical journey rather than a start-middle-end*" *(personal communication)*.

Recognizing one's vulnerability and the need for professional help

People with depression frequently report that they couldn't have gotten out of it without someone's help and support: "*If it weren't for them, I don't know what would have happened*"[113]. Although some people reject professional help altogether, most express a need for professional support to accompany them through the recovery process: "*There was always that net underneath me to catch me if I was falling and I couldn't stop it*"[110].

Recognizing one's vulnerability and seeking professional assistance is complex. People with depression are often in desperate need of help: "*You're going there to ask for help because you can't deal with it anymore*"[114]. This makes them particularly vulnerable to feelings of rejection and abandonment: "*What can be worse for someone with depression than to be abandoned?*"[114]. Some people express the underlying belief that mental health professionals do not really know in depth what they are treating because they have not personally experienced depression: "*I have experienced depression, for anyone who treats or writes about depression and who has not themselves been depressed is rather like a dentist who has had no experience of toothache*"[14].

The experience of receiving pharmacological treatments

Feeling ambivalent about antidepressants

A variety of experiences and a certain ambivalence have emerged in narratives about receiving pharmacological treatments: "*Depression cannot be cured despite medicine. However, I feel uncomfortable without medicine. I have to take it every day as long as I live, even if the fear of side effects bothers me*"[115]. Although subjective experiences vary across different cultures, most individuals think that antidepressants are needed to improve their symptoms and recover: "*I think they help me, they give me a sort of baseline to work from*"[116]. Even if they may not fully eliminate depression, they are perceived as helpful: "*[My antidepressant] does not eradicate the depression, but it makes me worry about it far less*"[16]. At the same time, they may be feared because of subjectively perceived dependence: "*One becomes dependent on the medication to be well and able to do things*"[85].

The experience of receiving antidepressants is poorer when they are prescribed without consideration for the individual person[117,118]. This may also explain why sometimes individuals feel that antidepressants are not targeting their core problems: "*I thought that medication was not dealing with the reasons why I was getting depressed*" *(personal communication)*. When psychiatrists explain in detail the functioning and the risks of the prescribed drugs, individuals with depression feel recognized as human beings and, therefore, adherence to treatment increases: *"There is stuff I don't know and stuff I don't understand, and he (the clinician) will explain it to me… and I like just being able to understand, it makes me feel a lot better; he helps me to have some objective view of myself"*[119]. However, at the same time, people may feel overwhelmed by the amount of technical information to digest and paralyzed to reach any decision: "*I don't know what the different pills do for me. It's difficult to cooperate and suggest changes when you don't have the necessary insight*"[120].

The experience of receiving psychotherapy

Feeling listened to and supported

People with depression generally experience psychotherapy as a safe space in which to feel welcomed and understood, and where they can speak freely about their sufferings and problems. Feelings of unprecedented relief and liberation ("*It was the first time I was able to talk about my feelings, and it was a big release*"[52]), and of freedom to be themselves and authentic without the need to hide their weaknesses, are sometimes reported.

One aspect frequently mentioned is the importance of sharing expert knowledge to improve self-management and self-efficacy. Involvement is important in restoring a sense of agency: "*It made me feel empowered*"[121].

Feeling improved through change

Individuals receiving psychotherapy describe several improvements in various aspects of their lives, both interpersonal and intrapersonal: "*My psychotherapy has improved my life… Everything has changed in my life… my relationships, everything*" *(personal communication)*. Psychotherapeutic benefits are often reported as increased self-awareness and improved confidence in the future: "*I feel that I'm armed now, that I can handle misfortune better because I've gained more insight into myself*"[111].

Self-improvement achieved through psychotherapy allows people to engage in relationships with other persons with better focus: "*That's my motto for the moment: I'm not investing in things that will gain me nothing. I do not think that's selfish, but more like healthy selfishness. It means considering yourself as well*"[111]. Psychotherapy can help them understand what they want in life, offering new insights and new perspectives: "*Psychotherapy made me reflect upon things and gave me some different ideas about situations that… needed to be looked at from a different perspective*"[122].

People may feel better because they know how to cope with their emotions and recognize their condition: "*I didn't even know I was getting depressed. [Now] if things are difficult, I can do something about it*"[110]. The success of psychotherapy also entails becoming aware of one's vulnerability: "*I remain fragile… which is where the skill of therapy comes in*"[123].

Feeling that psychotherapy threatens the self and is ineffective

Despite the above positive experiences, psychotherapy can sometimes be experienced as a threat to one's self and identity, and a challenge to values, beliefs and self-views: "*Giving up part of myself*" or "*Blowing my cover*"[52]. People may be afraid to start psychotherapy because it will expose them and show their weakness: "*I didn't want to be labeled as weak or mentally ill*"[52].

Some people with depression are dissatisfied with the purpose or efficacy of their psychotherapy: "*I still don't understand the purpose of talking about all these things; I often felt worse after the session*"[122]. They report that something was missing and that psychotherapy did not fully match their needs or expectations, and did not lead to recovery through change: "*A lot got untied in therapy, and some of those things are still loose ends, like not all pieces of the puzzle are put together yet*"[111].

Sometimes, the perceived ineffectiveness of psychotherapy is taken as evidence of the impossibility of future changes and of completely recovering: "*So, psychotherapy has ended now and once again I'm nowhere, it did not help, and it only cost me money, a lot of time and energy, and why? For nothing*"[122].

The experience of receiving social and physical health interventions

Empowering the self

People recovering from depression report that occupational therapy provides a space for them to feel empowered in their thoughts and feelings, and improves self-efficacy, self-confidence and self-esteem: "*It reminded me of the achievements in my life and gave me hope that I can do it again*"[124]. Sometimes, people are excited to discover new skills, of which they were unaware: "*I feel like I've done something, that I've achieved something even though it was so hard*"[125]. This discovery of one's abilities can lead to new insights into one's life challenges and the desire to solve them, nurturing hope in the future: "*If you want to achieve goals in your life, you must start with the old matters and deal with them, then focus on the new ones, then you will see progress*"[124].

People with depression generally feel that social interventions also helped to focus on practical matters: "*I did not know my creativity until I did beads necklace. It was relaxing, and I never had time to think about my problems*"[124]. Occupational therapy is also perceived as useful to distract them from their negative thoughts: "*I was very down, very emotional that day, but being in the fingerboard released my mind where I was, and I ended up being happy and laughing*"[124].

However, not all experiences are positive, and people with depression may feel discomfort in relating to others or being confronted with operational difficulties.

Sharing mutual peer support

Peer support is frequently experienced as a moment of sharing in which individuals can feel accepted and understood. Treating everyone's experiences equally allows individuals to feel less alone and strange: "*Everybody knows each other, and we all have our pains and problems, but we laugh about it, and you don't have to feel as if you're being tedious*"[49].

Sometimes people with depression who are engaged in peer support can make new friends that they cultivate with great care: "*God put somebody in my life at that time, she was like my angel…, and she pulled me up out of that dark hole*"[126]. Yet, others may feel uncomfortable attending peer support groups and discussing their challenges: "*I don't like to see people with obvious mental illness… It reminds me so much of me… I wish I had never joined the group*"[105].

Restoring bodily experience

Individuals living with depression report that exercise sets in motion their abilities to participate in life and engage with others: "*When I exercise, I'm not in the bubble, it feels like I know what everybody is up to, and I'm just like them working out*"[125]. Exercise can be about structuring, doing household tasks, or taking the initiative for more social contacts. It may provide a sense of relief from de-

pression: "*It kind of helps to rip open the cocoon you're in. It helps me to get the strength to crawl out of it, in a way*"[125].

People often talk about physical exercise as a way to re-become the person they used to be. Sometimes, they report a new vitality flowing through the body: "*I notice that my body softens and that I feel more alive, more in contact with my body*"[125]. Their narratives highlight how the bodily experience can be restored via physical exercise: "*It feels like I'm coming back to myself again, both body and mind. I'm taking them back*"[125]. Because of the improved bodily experience, people can report an improvement in their sense of self, since body and self together form an "embodied self" structured in a relationship of mutual interdependence[59,127].

However, other individuals report needing external motivation to engage in physical exercise: "*You need someone to practically drag you there. How could I make myself go if no one waits for me there?*"[125]. For many, lack of motivation has kept them inactive for a long time: *"I've never felt motivated enough to start a physical activity" (personal communication)*. Some people also express disappointment because physical workouts do not correspond to their expectations or are perceived as meaningless: *"I was hoping to feel some moments of euphoria, but there was nothing like that"*[125].

DISCUSSION

This paper follows and transcribes the lived words of individuals who have faced the experience of unipolar depression. We have given voice to these individuals' inner suffering, emotions, loneliness, and desperate need for help. The paper, as our previous one published in this journal[23], ultimately belongs to all the individuals with a lived experience of depression, their families and carers.

Our co-writing approach delivers a fresh integrated perspective on the experience of depression. The vividness of the subjective experience of suffering can only be captured by allowing personal insights to emerge, minimizing exclusion and misrepresentation of the affected individuals' perspectives[128]. Notably, we are not investigating whether narratives of depression adequately represent the condition: the main purpose of this study is to "give the word" to experts by experience and then integrate phenomenological insights rather than primarily testing researchers' hypotheses. In this context, this study outlines some essential (paradigmatic) ways by which depression expresses itself. However, it is evident that there is no such thing as a unique experience of depression, which "appears in various different clinical forms"[129], but rather a plurality of individual experiences. This evidence aligns with current clinical research efforts aiming at the clinical characterization of depressive disorders at the individual subject level[118].

Despite such heterogeneity, we found that most depressive experiences have broader themes in common, which express a radical change in the overall structure of one's overall relationship with emotions and the body, the self and time. Changes in the experience of emotions and the body include sub-themes such as feeling overwhelmed by negative emotions, feeling unable to experience positive emotions, feeling stuck in a heavy aching body drained of energy, and feeling detached from the mind, the body and the world. Changes in the experience of the self are described as losing sense of purpose and existential hope, mismatch between the past and the depressed self, feeling painfully incarcerated, losing control over one's thoughts, losing the capacity to act on the world; feeling numb, empty, non-existent, dead, and dreaming of death as a possible escape route. Individuals also report changes in their perception of time (experiencing an alteration of vital biorhythms, an overwhelming past, a stagnation of the present, and the impossibility of the future). These structural changes are inextricable aspects of an altered unitary experience, some kind of overarching existential change, an all-enveloping shift in one's sense of belonging to a shared world[34,130].

The world is seldom an explicit object of experience; rather, it is something that we are already practically, unreflectively immersed in, something that goes unnoticed when intact[131,132]. The experiences described confirm that depression disturbs something fundamental to our lives: this sense of being comfortably immersed in a familiar world[34]. Indeed, individuals often remark on the profundity of what happened to them[34]. According to our analysis, depression is, therefore, essentially a disturbance of world-experience[130].

The existential shift in how one finds oneself in the world can be expressed not only in terms of emotions, body, self or time. In addition, there are changes in the structure of interpersonal experience, resulting in an overarching feeling of being disconnected from other people. Individuals report struggling with communication, experiencing loneliness and estrangement, and perceiving stigma and stereotypes; these features lead to an overall loss of dynamism and openness to life. Individuals with depression find themselves in a different world, in an isolated, alien realm that is indifferent to others, painfully cut off from them or experienced only in terms of threat[34].

We also found that these experiences are highly variable across different cultures, ethnic or racial minorities, and genders. For example, in cultures whose members experience themselves as integral parts of a social community, depression is conceived less as an intra-psychic disorder and more as a bodily and interpersonal experience[5]. The loss of bodily vitality is, at the same time, a privation of emotions and self. The feeling of constriction of a trapped body cuts across the distinction between bodily and mental. This suggests that, in order to fully understand experiences of depression, we should avoid imposing dualistic distinctions upon them. The traditional dualism of mind and body is derived from the Cartesian dichotomy of positive sciences[133]; it locates the mind and affects exclusively inside the brain, a container contemplated in abstraction from the rest of the living, moving, environmentally situated unity of the organism[5]. On the other hand, psychological reductionism tends to attribute depression to intrapsychic mechanisms (e.g., faulty information processing[134,135]). In both cases, depressive experiences are disconnected from the body and put into an inner container[5]. As a result, the real embodied experience of individuals with depression is at best regarded as a secondary "somatization" process[5]. In contrast, the bodily experience of depression is the crucial dimension of a non-reductionist view. We should not understand depressive disorders as just an intra-individual state, localizable within the psyche or the brain, but as a detunement in

the literal sense – a failure of bodily attunement to the shared world of emotions[5].

We observed an individual variability of attitudes towards the recovery process. Recovery was described by some people as a journey based on their ability to recognize their vulnerability and the need for professional help, but other people just wanted to erase the illness from their memory, or experienced the recovery process very differently in different moments. Similarly, individuals were ambivalent about the experience of receiving pharmacological treatments (felt as needed but at the same time feared because of side effects and subjectively perceived dependence) and psychotherapy (some individuals felt listened to and supported, and improved through change, but others experienced threats to the self and concerns about its effectiveness). Social and physical health interventions were overall experienced as supportive, allowing self-empowerment, sharing mutual peer support, and restoring bodily experience. Good care and phenomenologically informed practices for persons with depression should be first and foremost based on understanding what it is like to receive these treatments, starting from the inner realities described in this study.

In conclusion, this study brings dialogue with experts by experience into psychiatric clinical practice and research. While biologically-oriented approaches tend to sideline and marginalize the personal perspective, we argue that depression cannot be understood if one neglects or trivializes that experience. In clinical practice, our phenomenologically-enriched study can complement biological approaches by allowing clinicians to empathize with persons with depression, because "the science of persons… begins from a relationship with the other as person and proceeds to an account of the other still as person"[136]. From the research viewpoint, our work can accomplish the purpose of moving away from the academic complexities of traditional phenomenological and philosophical studies, speaking in terms that everyone can understand.

We thus hope that our work will be useful to people who suffer from depression and those in supporting roles. By comprehensively improving the understanding of what it is like to live with depression, this study holds an educational potential to train health care professionals, and can be widely disseminated to experts by experience and family organizations to improve their mental health literacy. Health care providers and research funders may also access this co-developed source of lived experiences of depression to inform their agenda and strategic priorities[137].

Finally, this co-written journey in the lived experience of depression can also help us to understand the nature of our own emotions and feelings, what is to believe in something, what is to hope, and what is to be a living human being.

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