Abstract. “Illness works to deform and distort all the meaning and value one gives to one’s life” (Ahlzén, 2011, p.325). A feeling of terminal loss is experienced within the physical body as chaos floods the brain. Even language is incapable of fully addressing the internal tension that comes with illness, because it strives to make articulate the unpresentable or the abject. This review is directed towards analysing the experience of embodiment in illness, one’s relation to the self and to others, all within a particular context such as a place of constraint (hospital) or exchange (museum). The mediation between care and art practice, in fact, allows for the emergence of similar states that fluctuate between closeness and distance and between the unpresentable and the presentable as they enter in a process of dialogue. Such states allow the nurse and the artist to engage freely with the Other in a space defined by the intensity of narrativity. An empathic audio-visual tool called Sanctuary was created to serve a narrative, the ill person’s narrative. It is presented in the form of a visor which allows the viewer to participate, in fact, to bring to light and to expression all that the patient is ready to share, while being present to read between the lines of the silent narrative. An empathic encounter with the self, aims to be triggered through the process of participation in the artwork. The play of tension within a restorative, sheltering space is followed with planned empathic dialogue between the nurse and the ill person.

Keywords: transdisciplinarity, embodiment, presence, narrative, empathy, abjection

1 Memories Unfolding: the silent narrative

The two young nurses, carrying their fragility along with a basin of water, towels and sheets, dressing packs and saline solutions, enter the tiny cubicle on the left. They struggle to keep breathing, tasting the putrefaction. Pulling the curtain back, they greet the old lady in bed. She turns towards them with her dull eyes. They stop at the foot of the bed, not quite knowing why they feel so reluctant to leave this patient. One of the nurses retraces her steps and touches the old lady’s cheek. She looks down into the thousand-yard stare and a faint smile trembles on her parted lips. So much unloosen the bed clothes and wipe her face with a damp cloth; going over the plain of her forehead, across the ridge of her nose, along the mound of her cheek bones and over the crevice of her mouth, avoiding the cavernous eyes. The nurse on the old lady’s right side starts to lather the wash cloth and proceeds to soap the hands, taking care to get in-between the fingers, then up the arms, around the neck and along the jaw line and shoulders. She moves aside the crumpled sheet and washes the old lady’s breasts down to her waist. The soap floats aimlessly in the basin, leaving trails of cloudy water. Whilst one nurse washes and rinses, the other pats dry the loosening skin surprisingly soft to touch. A silence hangs in the air as they work in unison. Slowly, the old lady’s left leg is lifted up and the bandage unravelling with an imperceptible tremor. The air thickens and becomes solid. A face twitches and a throat softly cleared. The blackened leg is held suspended above the bed while being rinsed with saline, dried with thick swabs and a new dressing placed using disposable forceps. With the final bandage reapplied, the nurses proceed to turn the old lady over so as to finish her bath.

A prolonged, soothing sound escapes into the air like steam. Sheets are changed, dirty linen gathered, personal items sorted and the nurses are ready to move on to the next patient. They stop at the foot of the bed, not quite knowing why they feel so reluctant to leave this patient. One of the nurses retraces her steps and touches the old lady’s cheek. She looks down into the thousand-yard stare and a faint smile trembles on her parted lips. So much comfort. This end is the story of a beginning; a beginning that grows out of the overlap between care and art practice. One seeks to understand and reach out to the suffering other by creating new opportunities to do so. One needs to reveal ways to grow in awareness of all the narrative that is hidden below the surface of the ill self. This awareness will encourage the health care professional to bring to light and to expression all that the patient is ready to share, while being present to read between the lines of the patient’s story. The scope of this review is thus to show that art can be used within the hospital and clinical setting, enabled by nurses themselves, as a way of sustaining empathic dialogue and acknowledging all that is unpresentable and inarticulate in illness.

How does one start on a process that leads to understanding between two different disciplines? Gablik, a self-defined collage
The nurse is present

artist, looks towards the process of synthesis that brings to light all the subtle, interconnecting thoughts, feelings and actions that define our existence (Volckmann, 2007). This is the ultimate integral theory: a collective view of the world that presents multiple dimensions whose porous boundaries allow us to transcend all divisions. In this paper, the process of synthesis is used to weave a web of relation. It is hoped that through the testimony and knowledge derived from both disciplines, that is, care and art practice, the practitioner will gain further insight into the empathic process and its relation to the ‘lived’ experience of illness.

This paper is approached from the transdisciplinary perspective in order to give priority to the process of synthesis, rather than to the one of analysis. This leads to an exploration of what brings different concepts together so as to gain understanding of their point of interaction. Thus, one becomes more concerned with traversing the spaces in between concepts rather than with the depth of conceptual detail. Such spaces are revealed through practice, whereby the professional, by finding the time to be present as empathic listener, allows the client to narrate his or her story.

2 The Path of Narrativity

Sveneaus (2011) identifies the path of narrativity by which to explore the temporality of illness. He proposes that illness has a temporal structure and that it can be conceptualised as an alienation of past and future. It is only the present that appertains to the self as illness creates a rupture from the past and possible future. Ricoeur (1985, in Southall, 2013), in his book *Time and Narrative*, explains that in order for people to understand how their life has evolved, they need to create stories that serve to describe and enlighten their situation. In this way, they give an ordered sense to their experiences and relate their past to their present, in view of the possibilities of the future.

‘Bodies are realized, not just represented but created, in the stories they tell,’ Frank (1997, p.52) reflects in his book *The Wounded Storyteller: Body, illness and ethics*. This medical sociologist explains that illness narratives serve as stories being told through the body and not about the body. This highlights the performative and transformative aspects of this sort of narrative. A story is not only about its lived element but also about the experience gained from its telling and its reception. It is not about how truthful it is but how, by its retelling, the narrator helps us finally get it right and understand what it means to the narrator (Komp, 1996).

Furthermore, Frank (1997) distinguishes between three different aspects of the illness narrative.

- Chaos Narrative This part of the story is mainly a lived experience since it cannot be totally disclosed by the patient as it reflects the absurd quality of illness. It is the space of seemingly futile suffering with no hope for redemption.
- Restitution Narrative This part of the narrative is about a re-envisioning by the patient of the past history and possible future that appertain to his individual being. By this, patients aim to give a new meaning to their life and, by doing so, come back to their own health.
- Quest Narrative This is the story of what the patient goes through, from dealing with the chaotic situation s/he has been thrown in to finally embodying a new possible meaning in life. It is about transformation and the embracing of a new identity.

Frank (1997) focuses on the wounded person as being the centre of care ethics in relation to illness, showing us that we have a responsibility towards the emotional and psychological welfare of the ill person. He also pushes forward the importance of considering people who are chronically ill and whose disabilities are not a temporary disruption but part and parcel of their life. In these cases, illness narratives serve to help the ill person engage freely in the creation of an individual meaning of illness. Once the ill person’s need is defined, one must then understand the nurses’ perspective and how their position or stance influences the degree of closeness or distance allowed in their interaction with the patient.

3 The Nurse is Present

3.1 Exploring the closeness and distance continuum

“He whispers again, dragging the listening heart of the young nurse beside him to wherever his mind is, into that well of memory he kept plunging into during those months before he died” (Ondaatje, 1992, pp.3.4).

Being-there-for and being-with are aspects of relation that allow the health care professional to reach out to the patient and overcome boundaries that separate. The nurse is present by connecting with the patient. This is done through the interactive roles of listening and touch. One can listen by using ‘connective touch’, where the nurse is experienced as present by “being with” the patient. Listening also involves using ‘task-oriented touch’ where the nurse is present by “being there” for the patient (Fredriksson, 1999, p.1167).

‘Caring’ is fundamentally what nursing is all about (Leininger, 1986) and it is the culmination of thought, emotion and action that serve to address the needs of the patient (Bassett, 2002). A review of nurses’ perception of care showed that for the professional nurse, the interpersonal aspects of the nurse-patient relationship are valued the highest, while patients value both the provision of physical care and the provision of emotional bonds that serve to provide comfort (Bassett, 2002).

Conceptualisation of nursing care reveals the essential traits of caring, all within the nurse’s role: what the nurse does and what the nurse is. The traits include consideration, sensitivity, honesty, the ‘general approach’, ‘giving of oneself’ (Dyson, 1996), ‘enabling’ skills such as dedication, tact, cheerfulness, empathy, subtlety, humility and compassion, as well as intuitive knowledge that is an instinctive insight into the unspoken needs of the patient (Coulon et al., 1996).

In a study by Bush and Barr (1997), critical care nurses perceived as the most valuable caring behaviour, the ability to listen to the patient. Touching and seeing the physical body of the patient, considered as the very essence of caring, places the nurse in a position of privilege vis à vis the patient. In a study on oncology nurses, it was revealed that knowing the patient and establishing a ‘special’ bond, even though this might not always occur between the nurse and patient, provides a source of strength for both the patient and the nurse. This intimate proximity helps the patient overcome boundaries, trust and open up to the nurse so as to expose their thoughts and fears (Rittman et al., 1997).

Considering this sort of exposure, in view of the bond shared between nurse and patient, leads one to reflect on the course of empathy and how it is relative to consciousness. Central to this association is Edmund Husserl’s (1859-1938) phenomenological awareness of the human mind as not just simply residing within the confines of the physical brain but extending its reaches throughout the human body to overcome exterior boundaries of skin and enter the interpersonal world that surrounds the self (Thompson, 2001). Thus the human mind, being unconfined, consistently seeks to enter into dialogue not only with self but also with other. Thompson (2001) summarises the different aspects of this relation as being:
- embodiment - the mind is embodied within the physical self and also within its environment
- emergence - embodied cognition is made possible through the development of self-organised processes that interconnect mind, body and world
- self-other co-determination - the experience of feeling (affect) not only involves the whole brain but radiates to
The nurse is present

incorporate the entire body; the affective mind becomes the affective body whereby the emergence of affective states happen in a reciprocally co-determined fashion.

The empathic dialogue between two people is thus built on an empathic ‘recognition’ of each other which provides the individual with a conscious recognition of the self as an embodied creature. Consciousness is thus a product of the interrelation of selves and is consequently intersubjective. This makes intersubjectivity an open process that is dependent on an empathic understanding of the self and of others as embodied beings. Steinbock (1964, in Thompson, 2001) emphasised that the only way in which people can actually be experienced is in their “mode of givenness”. He calls the actual process (the way a person is given) “revelation”. He also identifies love or compassion as being its enabler.

Thompson (2001) calls in the work of Edith Stein (1964), a German Jewish philosopher (Husserl's student), who wrote her thesis “on the problem of empathy” and who went on to become an eminent spiritual theologian. Considering Husserl’s theory that the body as perceptual agent obstructs, in its physicality, the perception of self, Stein believed that through empathy, one gains another viewpoint. She believed that empathy is not a summative process but the holistic experience of another person. It involves a reaching out for the Other not as mere physical presence but as a living body. She talks of empathy as being reiterated, a way of grasping the self from another’s perspective, thus allowing the person to experience the self from within and without.

According to Määttä (2006), Stein's concept of empathy (1916) is a synthesis of Martin Buber's (1955) and Carl Rogers' (1959) approaches to empathy. In Buber's book Between Man and Man, dialogue is given the primary mediating role whereby a process of ‘crossing over’ facilitates the space of ‘shared meaning’ between two people. This empathic relation happens naturally, spontaneously and in an unconstrained manner. On the contrary, Rogers' client-oriented theory is based on a shared meaning that occurs from a detached position and as a consequence of one’s intention.

Due to nurses' fear of being engulfed by the patient’s experience of pain and suffering, Määttä (2006) suggested that empathy within the therapeutic nurse-patient relationship can be related to Stein's (1916) concept of empathy, which comprises three levels:

I. Experiencing the other as object

This is a second-hand, intellectual experience of a person's emotions and feelings. This stage is characterised by active listening and an effort to put the self in the other’s position.

II. Identification with the other

A merging of identities occurs with a deep understanding and awareness of the other (subject and object become one). This is an emotional, inter-human encounter with the lived quality of a parallel experience, yet still a non-primordial one.

III. Sympathy towards the other

A detachment occurs here and distance is reintroduced between the self and the other.

Määttä (2006) balanced patterns of closeness and distance using Stein's concept. This would help foster the degree of objectivity and control of self, associated with a professional stance. During the process of empathy, the nurse ‘bears witness’ to the patient by being actively engaged in listening for meaning. This will allow the evolution of the process of narration which helps the patient come to terms with the space of illness. It would also restore their individuality and connectedness with their life story, while encouraging them to reclaim their experience of illness from the medical metanarrative (Sakalys, 2003).

3.2 Exploring the presentable and unpresentable continuum

When engaging in empathic dialogue with a patient, the nurse needs to be aware that, at times, there is an unidentifiable, unpresentable gap in the space of relation. According to Cameron (2006), this gap is a consequence of the relation between the unpresentable and the presentable as they come within “extreme proximity to the edges of human existence” (p.33). The nurse is called to embody the tension arising from this particular space, a space that is unaccounted for. In order to explore the unpresentable-presentable continuum in nursing, Cameron (2006) points out that language is incapable of fully addressing this tension, because it strives to make articulate that which is unspeakable and will unfailingly resist coming to light. She proposes instead the weaving of a co-text, that allows for the assimilation of the Other, so as to enable an intertextual reading of that which is being enacted. “We must bear witness to the hiddenness of the being of the other...we must resist hermeneutic synthesis as we deal with individuals, families, communities, global areas where each have their own understanding of health and illness” (p.34).

Cameron (2006) brings to light the inherent subtleties associated with nursing practices such as the giving of bed baths and the endless acts of entering a patient’s room or pulling a cubicule curtain that allow the nurse to witness this fragility, this exposure. In encountering the unpresentable in others, nurses face the unpresentable in their own selves. This, they need to endure while carrying on nursing the unpresentable in others. The nurse is thus called to weave elemental acts of care that bear weight in a co-text that ‘reads between the lines’ of a patient’s story, a story that is about broken and, at times, abject bodies.

4 The Artist is Present

4.1 Exploring the closeness and distance continuum

Marina Abramović is a performance artist whose latest work revolves around presence, embodiment and empathy as a healing experience. “Presence is the only reality we have, there is no other reality”; through the art of performance, “performer and the public become one form, one entity” explains Abramović in an interview with The New Yorker (Dylon-Robbins, 2013). Due to the ephemeral and empathic nature of performance, art becomes “a connective tissue between ways of being and seeing” (Tan, 2008, p.11). Tan picks on Sigmund Freud’s concept of deferred action as a reciprocal relation between the occurrence of a significant event and its re-enactment or re-activation at a later stage in life. This concept shows that our receptive understanding of an important event necessitates the passage of time. This temporal delay is what makes one-to-one performance art, such as in The artist is present, a 2010 performance by Abramović which portrayed an intimate encounter based on empathic dialogue (see Figure 1). The actuality of the present moment is a shared witnessing between two people who activate the unconscious and tacit dialogue necessary to find a common and conscious articulation of personal meaning. The engaged self is now a proactive self who is no longer one of many but a person with identity. Thus, an intimate environment facilitates the reciprocal reading that takes place between the artist’s self and the engaged self and between gaps of articulation. “…our act of giving voice to a shared silent ritual binds us intimately. A familiar and ordinary human activity is re-contextualized into an immersive interaction, to allow for new meanings and understanding to emerge from… the collective embodied foundation of our subjective consciousness” (Lu, 2008, p.21).

“Our capacity to pre-rationally make sense of the actions, emotions and sensations of others depends on embodied simula-
The nurse is present

Rhythm 0

The necessity for this simulation is explained by the presence of mirror neurons in our brain that encourage us to learn through imitation and grasp a better view of the surrounding world. An empathic attuning process, through which beings can empathise with others, results through the mediation of art (Frank, 2010). Thus, a subconscious mimicking of action or of motion dynamics present in art, whether performative or visual in nature, heighten the viewer’s emotional response to the tactile sensations in the work and bring about a further engagement with it. Zeki (2001) concludes that it is the natural predisposition of the artist to explore and understand how the viewer will react and interact with visual stimuli.

Sontag (2003) discerns between ways people react empathically to a visual experience. This is especially relevant to the nurse-patient relation. If a person reacts from a subjective point of view and associates the ‘self’ with the visual stimulus, then empathic engagement is experienced. If, on the other hand, the suffering person or performance artist is perceived as ‘other’, then the empathic response will be dulled. In a 1974 performance called Rhythm 0, one observes Abramović looking away from her body in a pained and detached way (Abramovich, 2013). One notes the indifference of the participating spectator who, allowed to do whatever he pleased to Abramović with an array of objects at his disposal, did not recognise himself in the other. Frank (2010) notes that trauma, whether visually experienced as art work or witnessed in traumatic situations such as war, or illness one may add, elicits different empathic responses and disturbs one’s mental wellbeing. He ties this in with the concept of vicarious traumatisation where the individual experiences traumatic stress by simply witnessing the trauma narrative.

5 Exploring the Presentable and Unpresentable Continuum

Performance art facilitates the corporeal experience of the body’s physical and perceptual dimension by exposing “the limits and excesses of the body (that take them to) loci of extremity, the nearest possible to the concept of death...which is the limit through which the horizon of extoriety can be contemplated” (Merewether, 1996, in Escoda Agusti, 2007, p.291). This is made tangible by the concept of abjection as defined by Kristeva (1982), a critical theorist. Abjection is a subconscious reaction to one’s own subject that allows a bringing to light of one’s mortality. Abjection revolves around learnt rules and language that push the individual, from an early formative age, to engage in a social revulsion of the abject - that which can exist out of our body but which is also part of our body.

“Refuse and corpses show me what I permanently thrust aside in order to live...these body fluids, this defilement, this shit are what life withstands, hardly and with difficulty, on the part of death. There I am, at the border of my condition as a living being” (Kristeva, 1982, p.3). We recognise the abject around us in certain instances when meanings break down and the nonsensical enters our life. This throws order into havoc, identities into crises and systems into disorder. The abject is that which lies in the in-between, on the borders of familiarity (Frank, 2010).

The fleeting nature of artist Ana Mendieta’s (1948-1985) performances, as she negotiated earth-body boundaries, was registered in the intensity of the passing moment’s presence and aims to reconfigure culturally conditioned ways of perceiving. Her agency allowed her to act in a world that is in a continuous state of becoming. She pushes the audience to appreciate subjective reaction, by undressing her own subjectivity and putting on the cloak of Otherness. By dwelling in the “abyss at the borders of the subject’s existence”, Mendieta takes on an abject identity, “an interstitial space between the person and the animal...between flesh and feathers” (Sandoval-Sánchez, 2005, p.547). This peripheral act of being makes carnal all that lies hidden and repressed within and which is eventually “transposed onto the feared Other” (Sandoval-Sánchez, 2005, p.547). This work is associated with sacrificial rituals carried out in Afro-Cuban communities so as to “restore a loss or heal an illness” (Escoda Agusti, 2007, p.294).

This temporal investigation, or negotiation, of ways of being in the world leads to an internal journey into intimate spaces, where the body becomes a means of interrogating, not only subjectivity and perception, but also ways of being ill (Morris, 2011). Such is the work of photographer and writer Alíx Cléo Ronhaud, who experienced her embodiment through the mediating role of an “incarcerating” asthma (Morris, 2011). This affected the artist’s agency by introducing physical limitations. The feeling of a slow suffocation exacerbated by any form of exercise impinged on what the artist could actually do, redefining her body’s relation to the world.

Leder (1990, in Svenaeus, 2000), in The Absent Body, describes how the isolating effects of pain and illness on daily routines leads to a spatiotemporal constriction that brings about self-reflection. This, in turn, leads to a re-evaluation of identity, an exploratory search into understanding the nature and place of illness and the

http://dx.medra.org/10.14614/NURSEARTIST.2.1.2 http://www.um.edu.mt/healthsciences/mjhs
6 The Mediation between Care and Art Practice

The fluctuating mediation between care and art practice leads to a crossing over from one area to another, a sort of trespassing of borders where ideas in one field are seen to echo in another. Philosopher Michel Serres in his book *Rome: A Book of Foundations* (1991, in Connor, 2002) explains that being in ‘the middle of things’ inherently signifies a process of mediation. In his discussion on time, Serres proposes the image of the baker kneading dough whereby ‘time enters its folds and is constantly moulded’. The process of folding over takes the fluctuating shape of organic structures rather than the rigidity of linear symmetry. This leads to a dynamic approach to thought processes, where interaction is ‘kneaded’ into being. This is in opposition to the idea of analysis which involves the separation of one thing from another. Serres’ milieu finds its fulfilment in-between channel and environment. Channels of communication, whether in a hospital context or a museum, are presented as ‘involutions of time and space, rather than simply movements between poles’ (Serres, 1991, in Connor, 2002, p.3). Thus, mediating relationships between distance and closeness or the presentable and unrepresentable should be visually pictured in this way rather than as a linear dimension.

The point of interaction between care and art practice is precisely the need for empathic connection that allows the process of enquiry within the museum space and the process of narration within the hospital space. Kwon (2004) sums up the developing attributes of site-specific art seen as movement towards a concurrent dematerialisation of the site, together with a deaesthetisation and dematerialisation of the artwork. An appraisal of the artistic object and aesthetic experience gives way to an experience or process that provokes within the viewer an analytical reaction. The relationship between the art and the site is no longer performatory but a metonymy for her impending death and its causal illness. In one photo in particular, by placing the camera on her chest while lying down, she creates a dual portrait that bears witness to her struggle to give meaning to her illness. In one photo in particular, by placing the camera on her chest while lying down, she creates a dual portrait that bears witness to her struggle to give meaning to her illness. Roubaud’s photographic testimony provides an invaluable piece of evidence to profound acts of being, sometimes on the border between the health care giver and the receiver. It can help foster understanding of self and others. Although the conceptual development of the artwork *Sanctuary* (Baldacchino, 2014) (see Figure 2) is bound to the physical context of its use, it is not necessarily dictated by it. It was created for use within places of constraint such as hospitals and adapted to places of exchange such as exhibition settings. This artwork became a mobile space that can be ‘consumed’ anywhere, making the primary site as elastic as its discursive one. This artwork also challenges the nature of artistic authorship, being designed so as to do away with the need for the artist to be an essential part of the process of its dissemination. The nurses in this case are given autonomy to handle the artwork themselves and use it as a way of triggering or encouraging the empathic process during therapeutic dialogue. However, it still highlights the role of the artist as a promoter or narrator, “because the signifying chain of site-oriented art is constructed foremost by the movement and decisions of the artist, the (critical) elaboration of the project inevitably unfolds around the artist” (Kwon, 2004, p.51). A recent shift from site-specificity to community-specificity, noted by Kwon (2004), pushes the artist to engage the audience, particularly marginalised ones, in the artistic process. Chronic and serious illness does in fact push the individual into a sort of exile, both socially and physically (as embodied experience). Falling under the title ‘new genre public art’, work in this area is centred on a humanitarian plight. Such work focuses on ‘pleading the case’ so as to create awareness of suffering endured by individuals within specific communities. The work *Sanctuary* (Baldacchino, 2014), humanitarian in essence, is thus concerned with social awareness, as is the exhibition setting for the project. However, *Sanctuary* within the hospital/clinical setting (Figure 3) tries to go beyond this boundary by aiming to create understanding primarily for its user, the marginalised, the exiled and the alienated themselves.

7 Conclusion

As we turn to face each other, “the ethical and the spatial cannot be prised apart... this gives us our initial sense of a responsibility to something beyond us” (Morris, 2004, p.176). The nurse, in caring for the ill person, is thus called to look between scars and sutures, over crusts and wounds, around colostomies, drains, infusions, monitors, through necrotic, bileous smells and beyond the pus, vomit and excrement to understand and bear witness to profound acts of being, sometimes on the border between the here and there, so as to give empathic testimony to human suffering. Art as a powerful, symbolic language provides an invaluable tool to help sustain this process.

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The nurse is present

Figure 2: Installation views from *Sanctuary - Where is the Patient?* (Baldacchino, 2014) at the exhibition *Propolis: Artwork as Social Interstice*, St. James Cavalier, Valletta, Malta (photographs by Anna Runefelt).

Figure 3: An Empathic Tool from the series *Sanctuary* (Baldacchino, 2014) exhibited at St. James Capua Hospital, Sliema, Malta (photograph by Anna Runefelt).

http://dx.doi.org/10.14614/NURSEARTIST.2.1.2  http://www.um.edu.mt/healthsciences/mjhs
Acknowledgements

I would like to thank Dr Raphael Vella B.Ed.(Hons), M.Ed., Ph.D.(Lond.), Senior Lecturer with the Department of Arts and Languages in Education at the Faculty of Education, University of Malta, for ‘always bringing out the best in his students’.

Funding

This research has received no specific grant from any funding agency in the public, commercial or non-profit sector.

Conflicts of Interest

The author reports no conflicts of interest.

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