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“Doing hope” as a possible way towards a responsive occupational science

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ABSTRACT

Europe is facing many major and rapid changes, which have direct consequences for the everyday lives of people experiencing diverse situations of vulnerability. Changes in health care systems, migration, and a growing population of elderly people are just a few examples of these changes in Europe. New ways of living and the struggles associated with them, urge our community to seek sustainable ways towards social justice. I choose to speak from my position as a hybrid scholar (from the in between); formed and trained within diverse epistemologies to reflect on these issues. I aim to open a dialogue about possibilities and responsibilities to become responsive to persons and groups, where failing infrastructures in our communities expose forms of vulnerability. What can occupational science do regarding populations whose vulnerabilities are exposed? What kind of science is needed to meet these challenges? To reflect on this, I will draw on my research experiences of engaging in community building and my teaching experiences preparing future occupational therapists to face these emerging topics. I introduce the concept of ‘third space’ as a possible way for knowledge creation embracing democratic collaboration, negotiation, and contestation in research and learning contexts. I will conclude by engaging in a critical reflection about the epistemic privilege where occupational science is founded, and the urgency to explore and create other frames of collaboration and dialogues that allow us to construct a more just world together.

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When I asked my more experienced colleagues about how to write a keynote, one of the answers was that I was probably invited to talk about what I have been doing as an occupational therapy scholar and in relation to the topic of this conference ‘Europe in transition: Impact on occupation and health’. I took this advice, but I stretched it a little more, so I am going to talk about my epistemological roots, the way I learn to understand knowledge, that somehow explains my approach to research and helps me envision a possible future for occupational

therapists and occupational science scholars. In the ongoing conversation about the relationship between occupational science and occupational therapy, Molke, Laliberte Rudman, and Polatjko (2004) noticed that I understand occupational science as an outgrowth from occupational therapy, not as an independent entity. This stance is grounded in my reluctance to replicate a Cartesian dichotomy and dualistic understanding of praxis.

To go to the roots, let me start with a poem by Pablo Neruda; a poem that has been one of the

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compasses of my life and also as a scholar. It is a part of the political poetry of Neruda, assembled in the book called '*Canto General*', written during one of his periods of exile from Chile (Neruda, 1950; Schmitt, 1991). It reads as follows:

I've been reborn many times,
 from the bottom
 of defeated stars,
 rebuilding the thread
 of the eternities that I populated with my
 hands,
 and now I'm going to die,
 with nothing else,
 with earth
 on my body,
 destined to be earth
 I want to be in death with the poor
 who didn't have time to study it,
 while they were beaten by those who have
 Heaven divided and arranged.

As a scholar, I have strived to be close to those beaten by others in power, close through my profession to the marginalised and oppressed by different forces and in different forms. I have worked as an occupational therapy scholar in mental health and with human rights in Latin-American and European contexts. The experiences of these very different backgrounds have turned out to be more than just episodes of my life and identities; they have become a field of tension and friction between modes of practices and epistemologies, particularly regarding the understanding of knowledge creation (Pérez, 1998).

Lately, with the help of postcolonial literature (Bhabha, 1994), I have articulated this field of struggle as hybridity, as a conscious positioning of myself in the 'in between'. In between, as a position of resistance to some established boundaries, movements, turns, and models coming from occupational therapy and occupational science. This, to give some space to apply other modes of knowledge learned back in the South. Not just the geographical South, but the epistemological South (Santos, 2014; Simó et al., 2018). Echoing other scholars within our discipline (Guajardo et al., 2015; Simó et al., 2018), I understand the epistemological South here as the neglected and underrepresented

knowledge created by the global South due to the hegemony of Western domination and modes of knowledge creation. This 'in-betweenness' has, for example, allowed me to attempt to innovate theory and act politically, to think beyond narratives of unitary cultures, and to focus on those moments or processes that are produced in the articulation of cultural differences (Vidal, 1988). This in-betweenness has helped me to initiate or enter spaces as new sites for collaboration and contestation, in the act of defying hegemonic ideas of society and creating other grounds (Bhabha, 1994; English, 2005). This approach has been useful when conducting research about the everyday life of older adults living in nursing homes immersed in a changing health care system in Sweden (Mondaca, Josephsson, Borell, et al., 2018; Mondaca, Josephsson, Katz, et al., 2018, Mondaca et al., 2019) and in planning psychosocial interventions for asylum seekers and refugees coming to Europe. At this point I have dared to challenge my own colonized understanding on knowledge creation, and instead applied this hybridity in my current context in new forms. I am still in the process of uncovering how these epistemologies and theories, coming from totally different contexts, dialogue with each other in my daily praxis. It is actually a challenge to take a pause in applying the hegemonic traditions in research and, at the same time, attempt to articulate what otherwise I have been using as practical knowledge.

From this in-betweenness, I invite you as a reader to dialogue with some foundational scholars that imprinted my way to approach research and education. I also invite you to visit my current field of research through visiting some lessons learned with residents and staff of a nursing home in Sweden where I have been working (Mondaca, Josephsson, Borell et al., 2018; Mondaca, Josephsson, Katz et al., 2018; Mondaca et al., 2019). With this article, I aim to expose different ways of understanding and facing vulnerability, as a concept that needs attention within the current situations challenging European societies and societies in other parts of the globe. I invite you to reflect on the social responsiveness we are being demanded to take by our human fellows in less privileged positions in these contexts, such as asylum seekers, refugees

(Morville et al., 2014; Morville & Erlandsson, 2013; Roos et al., 2018; Trimboli & Halliwell, 2018), and people living in institutions.

Coming from a colonized theoretical space (Guajardo & Mondaca, 2016), it is still rare to encounter Latin American scholars who have influenced theories and praxis within occupational science, with the recent exception of Paulo Freire. So, in this presentation I take the opportunity to share this platform with some 'big influencers', who have been absent from the dialogue so far. Sharing this platform with these Latin American influencers is not a random choice, but a way to make visible those invisible in this occupational science context. They are not my heroes, but part of my epistemological roots.

To introduce these thinkers, I will adopt dialogue as an act of opening, grounded in the idea that we are not defined or finished but constantly emerging in the social realm, through the presence and engagement with the other (Frank, 2005). This approach was inspired by Bakhtin (1981), who argued that we become ourselves only while revealing us for another, through another, and with the help of another. Bakhtin argued that humans have no internal sovereign territory; that one pivotal human condition is our un-finalizability that emphasises the notion that a person is never fully revealed or fully known. From this perspective, humans are always on the boundary, always un-finalized (Baxter, 2009). The recognition of our own positioning on the margin in each encounter, will, according to this approach, generate better chances for dialogues. Ontologically, this approach holds the assumption that human beings are in constant, emerging, and contingent construction of identities (Vidal, 1988). In line with this assumption, the dialogical perspective argues that identities are formed through engagement with others. According to this approach, the acknowledgment of 'the other' will bring mobility and openness in language and discourses, and in actions I will add from an occupational perspective.

I invite you as a reader to engage with four guests, who will help me to disentangle this conversation. With their help, I invite you to explore and reflect on different ways to see vulnerabilities; a crucial issue to critically reflect on in order to be responsive as scientists.

Inspired by the work of Butler et al. (2016), I understand vulnerabilities as the exposure of ourselves when social infrastructures fail in their fundamental functions or get corrupted in different ways. The global capitalist neoliberal agenda has been a major actor exposing vulnerabilities in several contexts in Europe and elsewhere. The ongoing protests ('*estallido social*' in Spanish) in Chile during recent months has demonstrated how the everyday life of several generations has been disrupted and impoverished by the neoliberal model creating social inequality (Amnesty International, 2019). But as Butler et al. (2016) argued, this exposure presents both vulnerability and different forms of agency and resistance, as has been the case of these particular protests demanding dignity in everyday life. Resistance grows and inhabits people's living situations of vulnerabilities and is expressed in different ways.

My first guest is Ignacio Martín-Baró, who was born in Spain and grew up while Franco was in the seat of power. Martín-Baró became a priest and later travelled to Latin America. According to Martín-Baró, El Salvador was the greatest discovery of his life. He also lived in Ecuador and Colombia, and studied philosophy and psychology in Latin America, the USA, and Europe (Portillo, 2012). He maintained correspondence with Viktor Frankl, which had a significant impact in his doctoral thesis (about being and suffering) and shaped his worldview. He undertook a masters and doctoral degree in Chicago, was a guitarist, and spoke several languages. In the 80s, he gained attention calling for a critical and emancipatory social psychology. He was a keynote speaker at several conferences, used as a strategy to survive by being in the public eye. This was a way to serve as a witness who could denounce the atrocities of war and the human rights violations in El Salvador and other Latin American countries during that time. Martín-Baró was a pioneer and founder of the liberation psychology movement, which had a great impact in social sciences, communities and, in particular, a key influence for occupational therapy praxis in Latin America. He was murdered because of his ideas, praxis, and resistance when he was 47 years old in 1989.

There are some key lessons of the praxis and ideas of Martín-Baró that I would like to highlight here, because they relate to the challenges affecting us in Europe and could provide some guidance in our roles as scientists. Martín-Baró understood science as a dialogue, as an opportunity to deeply engage with populations suffering disruptions and oppression. Not as an academic exercise but as a profound commitment with the meaning and the transformative mission of creating new ways of living for those resisting oppression. He called scientists to transform their own practices and our societies by aligning ourselves with those struggling for justice and equity. He proposed and embodied a new praxis of commitment with social justice and had the ambition to humanize the world (Martín-Baró, 1995, 1996). He proposed it as necessary to decolonize our common sense, our everyday life, what we take for granted and challenge it. Why should we accept as natural what is inhibiting, constricting human freedom in any form of oppression or disruption? Why should we normalize that people fleeing for their lives are deported back to precarious everyday situations? Why should we normalize that people do not have any influence in their everyday life while growing older, because they live in a nursing home? These are just current examples of oppressive situations that I have been working with in my research. I am sure many more normalized oppressive situations come to your minds from your own contexts.

Martin-Baró saw those living in oppression as enacting resistance and creating solidarity. Human expressions were seldom highlighted by social psychology back then. Responsiveness meant, to him, taking the side of the oppressed; not theoretically but as an everyday life commitment. How much about the solidarity, reciprocity, resistance, collective organization, and transformations that emerge from our human fellows engages us within our field? How could we envision through our research more humane societies? (Galvin et al., 2011; Wilcock, 2001). How will we respond to Martín-Baró about our commitment with those experiencing social struggles and inequalities? How is occupational science contributing to erase social inequalities? How does our work liberate others from oppressive conditions in everyday life?

My second guest in this dialogue is Alejandro Guajardo. He is the director of the first occupational therapy program in Chile that claims to be decolonized. He is one of the leaders of a movement called ‘Epistemologies of the South’ and a main fellow of the ‘Critical occupational therapies’ group of scholars (Guajardo, 2014; Guajardo & Galheigo, 2015; Guajardo & Mondaca, 2016; Simó et al., 2018). I asked him some questions about our role regarding vulnerabilities that have been exposed and the role of occupational therapy and science in facing societal challenges related with social inequalities.

Mondaca: *What are your thoughts on vulnerability?*

Guajardo: *Let me start by arguing that occupational therapy fulfills an important role in the stability of social systems. Our actions as occupational therapists, what we do in our specific contexts, do not escape the ethical and political, as they reproduce or transform various forms of government, that is, different ways of building social life. Today's reality calls us to work towards inclusion, citizenship, participation, justice, among others. All domains related to human rights, quality of life and psychosocial well-being and populations systematically disfavored by the socioeconomically and political systems that force people into situations of vulnerability.* (Translated from Spanish by the author)

Chile is considered one of the most extreme neoliberal economic systems and some of the social struggles that this economic framework creates are people engaging in drug abuse from a young age, homelessness, consumption rates ending in indebtedness, sometimes for life, high prevalence of mental health disorders (World Health Organization, 2020) and other social problems (Quijada et al., 2018).

Guajardo continued his reflection:

We fail when we believe that these situations of vulnerabilities are due to the individuals and not the social system we reproduce. How do we challenge this social system? Through being political, because

political decisions affect people's everyday lives. We fail when we believe that there is one way to create knowledge, the scientific; there are several ways of knowledge creation, because the socio-historical realities are different. Examples of different sources of knowledge are applied sciences and their long history, art, community movements and much more. When including other modes and types of knowledge in our praxis, we are better prepared to start addressing vulnerabilities, because that is where a common ground for transformation of social conditions emerges.

Mondaca: What do you think about the contribution of occupational science regarding the challenges we face as societies?

Guajardo: To investigate means to interrogate something relevant to the reality, and that is possible to do in many ways. Science is just one of those ways. I see the origin and the development of occupational science as aiming to be foundational, somehow being able to claim: now we are scientists, leaving aside/behind other ways our discipline has been building knowledge. Understood like this, the historical emergence of occupational science is just a dimension of the many occupational therapies that exist. Occupational science development here in Chile is a mimic of the hegemonic development of the North, not responding to the citizens' struggles but to power ambitions.

As you can see, this more radical position of Guajardo has to do with the historical development of occupational science and therapy in Latin America, where it is experienced and interpreted as a new wave of theoretical colonialism (Mignolo, 2009). I think it is worth reflecting on how occupational science and therapy can reproduce mechanisms of dominance and positivism, that contradict the emergent transformative discourse.

My third guest is the community of a nursing home in Stockholm, Sweden, and the research that I have been doing with older adults living in nursing homes. The first important thing to mention is that it is not self-evident that the

social and health infrastructure of a welfare system could be somehow failing to provide good care and the possibilities for a good life for older adults. This has been a surprising insight for the international community engaged in this field. There is an assumption that these types of struggles do not exist in Scandinavian countries, however, there has been a progressive dismantling of the welfare system in Scandinavian countries (Magnussen et al., 2009). The housing standard of the majority of the eldercare facilities is something that, in other contexts, one could only dream about. However, thanks to the advances in medicine, people are living longer, and that should be a good thing, right? Something to celebrate, something that humanity has been searching for forever. So why is it that we are not celebrating and honouring the life of these older adults who fought to create universal welfare systems in Sweden? Indications of occupational injustice experienced at nursing home in Sweden have been captured through different ethnographic studies (Harnett, 2010, 2014; Mondaca, Josephsson, Katz et al., 2018).

Excerpts presented in Mondaca, Josephsson, Katz et al. (2018) illustrate how a nursing home resident experienced a trip to a dentist appointment as meaningful and stimulating, due to the contrast with everyday practices at the nursing home. These findings are in line with the higher incidence of mental illness among those 65 years or older who receive support from the elderly care or the municipal health care, compared to persons without such intervention in Sweden (Heurgren, 2018). Discourses of successful aging and active aging, and the influence of the new public management in health care are some of the factors affecting everyday practices in this context (Gilleard & Higgs, 2011; Higgs & Gilleard, 2014). The phase when older adults face the vicissitudes of living with chronic conditions and in need of permanent assistance has been metaphorically described by critical gerontologists (Gilleard & Higgs, 2010) as a social 'black hole', where light itself disappears.

In the particular nursing home where I worked for almost 4 years during my doctoral studies, one of the problems was that the everyday life of these adults was dominated by institutional routines that inhibited and constrained

more familiar forms of spending time and living everyday life (Mondaca, Josephsson, Borell, et al., 2018; Mondaca, Josephsson, Katz, et al., 2018; Mondaca et al., 2019). We approached this issue by making use of the theoretical resource of third space, borrowed from Bhabha (1994), to initiate collaborative praxis deeply grounded in the nursing home community. The community based and collaborative approaches (Suarez-Balcazar, 2005) adopted allowed us to make an impact on people's lives, on their every day, informing, transforming, and affecting how care should be shaped if grounded in the residents' needs, dreams, and possibilities (Mondaca, Josephsson, Borell, et al., 2018; Mondaca, Josephsson, Katz, et al., 2018; Mondaca et al., 2019). Examples of this collaborative approach were working on the creation of activity programs grounded in the nursing home residents' desires, interests, and capabilities (Mondaca, Josephsson, Borell et al., 2018) and the creation of collaborative projects with the staff working at the nursing home to promote a humanistic and occupational perspective towards their work with the residents (Mondaca et al., 2019). The approaches used had a strong occupational focus. A focus in everyday life, as the intersection of societal discourses and subjectivities. We immersed and created new forms and understandings of everyday life in this context, as the field where we make big and small fights, give up on rights, or put up resistance. We made alliances with the nursing home community.

Bhabha's (1994) insights stress the discontinuous nature of the location of emergent cultures or, third space cultures, where new identities and affinities are restlessly forming. Through aligning ourselves with the nursing home community, including residents and staff, we were able to reveal and maybe initiate a new culture of care, based on the idea that people can own their lives despite being in need of assistance; enabling staff to make partnerships that would help to improve the residents' lives but also the staff approach to their work with older adults. We could partially bring to the fore front and reward characteristics of everyday life such as solidarity and fellowship, to transform this institution (Mondaca, Josephsson, Borell et al., 2018; Mondaca et al., 2019), making it less oppressive. Through collaborative

research, we could also address social sustainability in these contexts by starting a dialogue; training and empowering the staff in new practices of care (Mondaca et al., 2019).

The collaborative approach applied when working with the nursing home community was natural for me, aligned with other kinds of community building and community-based practices applied by occupational therapists in certain contexts (Guajardo, 2014). While conducting these studies, we set in motion a network of actors related with the nursing home community, including family members, occupational therapy and photography students, and the day-care centre and school from the closest neighbourhood. All this was in order to identify and connect local social, sustainable resources, as proposed while conducting collaborative research (Reason & Bradbury, 2008). The process of building partnerships with the nursing home community at first created a lot of resistance, in my academic setting and in the care setting. Surprisingly for me, this was not how science was expected to be conducted. This was not 'sanitized science', using the metaphor of Lilian Magalhães (2012) in her fictional conversation with Paulo Freire, as the alliance with the nursing home community was 'contaminated' by a bit of unconventional hope and love. Through research and community building we were 'doing hope' in this setting (Weingarten, 2000), and seriously trying to make a social impact by addressing neglected issues of the nursing home community. Our academic culture privileged us to measure our academic success in terms of impact factors of publications, more than through awarding the social impact our research could bring to current social struggles. Maybe we have adopted this part of the academic culture uncritically, without resisting it enough or proposing alternatives?

Now I will transition to another dialogue, this time with a colleague from a country on the border between eastern Europe and western Asia, in the Caucasus region of Eurasia. Georgia, a country with no more than 4 million people, currently presents many health and social challenges (World Health Organization, 2017). As a consequence of the economic system, Georgia also faces the phenomenon of women moving to work in Asia or countries in Europe, creating

what has been known as ‘the skipped household generation’ (Chen et al., 2014), with children being raised by grandparents and the emergence of severe health and developmental issues in children. Georgia is also struggling with problems caused by internal displacement (Mitschneck et al., 2009), due to occupation of territory by Russia. I asked my colleague Nino Rukhadze, a teacher and practitioner in Tbilisi, about the current social challenges in relationship to occupational science and therapy.

We do not know much about occupational science to be honest; we have so many other priorities before that. Here the health care system is very limited, so occupational therapists are working in pediatrics, because that is covered by the health care system or health insurance system. Children are, of course, prioritised as the most vulnerable within the health care system. Rehabilitation of adults, the care of the elderly, and psychosocial problems are far away from our professional field and current practices. Tbilisi State University offers the only occupational therapy program; 10 teachers work part time, because their other jobs allow them to take this poorly payed job ‘as a luxury’. But we are not doing research; we are not connected with other countries doing research apart from the students’ projects lead by Hanneke van Bruggen. (Author’s notes of the conversation held in English)

My reflections about this piece of the conversation with Rukhadze concern the uneven development of both occupational science and occupational therapy, and the limitations in disseminating and sharing knowledge despite living in a technological era. What is the point of advancing in research, theory, methods, visibility, or gaining status if we cannot even reach our close neighbours and colleagues? How many other countries are in similar positions as Georgia? The capitalist economy and neoliberal systems have now produced obscene realities of social inequalities where people struggle in their everyday lives, giving up on freedom and dreams for a better life. Those realities cannot keep escaping from sight. How many

neglected realities are there within our countries? How do we advance in meeting these needs, creating new forms of collaboration, validating other types of knowledge?

The intention of this paper was to reflect upon possible directions that allow occupational science to be responsive towards the multiple societal challenges produced by social inequalities created, maintained, and exacerbated by the neoliberal agenda. Well, I do not have the answers. But I truly hope that I have unsettled you enough to reflect once again upon what we are doing, in which direction are we heading, how we are using our positions of power. From my guests in this dialogue, I highlight four issues of relevance that could help occupational science be responsive towards the current challenges. Firstly, the urgency to commit with communities experiencing disadvantages in participation in our local communities. As Martín-Baró (1995) proposed, this will need a critical revision of occupational science from within, in terms of being reproducers or transformers of oppressive and neglecting systems. Secondly, inspired by the dialogue with Guajardo, I believe it is crucial for scientists to recognise other forms of knowledge creation in order to be responsive and create sustainable collaborations grounded in everyday practices. Traditional science has been the main mechanism to generate what Foucault (2003) named ‘subjugated knowledges’, where the scientific method has been hegemonic in terms of knowledge production. Thirdly, the message from the nursing home community in Sweden is that even in welfare societies, marginalization and occupational injustice exists, and we should not neglect these realities. A final issue based on the dialogue with Rukhadze is a call for action to create a more even dissemination and creation of knowledge where we can support colleagues struggling to move forward in their local contexts, as was promised (Molke et al., 2004). As a discipline, we could be ‘doing hope’ by being accountable in our commitment for justice for those communities and individuals living their lives in oppressive and alienating ways due to structural inequalities.

Occupational science and therapy have extraordinary possibilities to address vulnerability when infrastructures fail. It is in our natural

domain to ensure that these infrastructures humanize and not the contrary. We can reproduce or resist oppressive conditions, as individuals and as a discipline. We can also build better societies. We seem to be in need to commit to those disfavoured by their socioeconomic and political contexts. We need to seek alliances that will bring community building, agency, and capabilities into their lives in our local contexts. Experiences coming from other epistemological roots have taught us that there are more sources for knowledge creation beside science to be embraced and used to close the gap between diverse social realities.

I will insist on the need to be aware of our positions of power, and instead of using it for self-reward or academic prestige, share our positions by building collaborative initiatives that transform this world radically, into a more humane one. I believe that we all can be responsive to the challenges we are facing in our societies, in large, medium, and small scales. Dare to start with demarcated and specific projects, and find more synergy partners to enlarge and expand an agenda of justice and equity.

Allow me to finish this paper with a quote from the first female Literature Nobel winner, which was discussed many times with the nursing home community I worked with. Selma Lagerlöf, an idealist and a woman ahead of her time who took on the fight for social justice through her writing, as her duty. “Jag är inte alls fallen för högmod och fåfänga, men däremot vill jag sätta världen i rörelse” [I am not inclined towards pride or vanity, but I want to put the world in motion] (Palm, 2019, p. 321). I want that too, but not in any direction except towards doing hope by pursuing social justice and equity. There is a word in mapadungún, the language of one of the original people of the south of Chile and Argentina, called Peumayén which means something close to the composed word dream-place. I invite you to strive for dream-places of solidarity, equity, and social justice. I will keep using my position as a scholar for these purposes. What will you do?

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