World Federation of Occupational Therapists Bulletin

ISSN: 1447-3828 (Print) 2056-6077 (Online) Journal homepage: http://www.tandfonline.com/loi/yotb20

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To cite this article: Nadine Blankvoort, Muzeyyen Arslan, Ani Tonoyan, Ahmad Q. Damour & Liliane Mpabanzi (2018): A new you: A collaborative exploration of occupational therapy's role with refugees, World Federation of Occupational Therapists Bulletin, DOI: 10.1080/14473828.2018.1526560

To link to this article: https://doi.org/10.1080/14473828.2018.1526560

WORLD FEDERATION OF OCCUPATIONAL THERAPISTS BULLETIN
https://doi.org/10.1080/14473828.2018.1526560

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A new you: A collaborative exploration of occupational therapy's role with refugees

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ABSTRACT

Theoretical works in occupational therapy and occupational science have explored the refugee experience through an occupational lens, and explored the potential for occupational therapy in this field. Currently, there exists a lack of literature which includes refugees in these explorations. Recognising the western-bias present within occupational therapy, it is important that refugees are part of a co-produced response. This article presents findings of a workshop held in the Netherlands, where four co-authors with a refugee background and one occupational therapist explored the definition of occupational therapy, the role it could have with refugees, and what is required from the profession to take on this role. Reflections suggest that occupational therapy has the potential to be a *connector*, *matchmaker* and *translator*, working towards societal participation. To do this, occupational therapists must critically reflect on assumptions embedded in occupational therapy, and must be aware of how structural systems influence participation of refugees.

KEYWORDS

Displaced persons; refugees; critical perspectives; co-production; participatory research; societal participation; occupational therapy

Introduction

> Occupational therapy is a discipline which investigates the causes of issues in participation, confirms the desired end results of the client and from there, together with the client, searches for solutions to these issues in order to improve participation in society. (Definition of occupational therapy created by co-authors with a refugee background)

Occupational therapists have always been interested in work with refugees[1]. In fact, one can argue that this is where the foundational roots of the profession are based; a profession born out of a response to groups arriving and attempting to resettle in America (Frank, 1992). Though over time occupational therapy theory and perspectives have aligned more with the biomedical realm (Dickie, Cutchin, & Humphry, 2006; Gerlach, 2015; Magalhães, 2012; Phelan, 2011; Whalley Hammell, 2015), it cannot be denied that the interest for displaced persons, and an advocacy and rights-based focus, has remained. Recognising the growing attention in this field within occupational therapy in recent years, there are also important gaps in the work being done.

When reviewing publications to date, there exists an ever-growing and inspiring body of research on occupational therapy with refugees. This literature which explores the experiences of refugees' occupational deprivation have added a new perspective and focus to the discourse on forced migration (Crawford, Turpin, Nayar, Steel, & Durand, 2016; Huot, Kelly, & Park, 2016; Morville, 2014; Morville & Erlandsson, 2013; Smith, 2015; Trimboli & Taylor, 2016). When critically exploring the literature base to date, there are some gaps in the current body of knowledge in occupational therapy literature on refugees. Firstly, most of the literature being produced is an exploration of the potential for occupational therapy, written by and for occupational therapists, published in journals for occupational therapy audiences. Authors have explored the multiple settings in which occupational therapists can work with refugees (Algado, Gregori, & Egan, 1997; Smith, 2017), and explored how the role of occupational therapy, can be further developed within this field (Crandall & Smith, 2015; Suleman & Whiteford, 2013; Trimboli, 2017). This profession-centered approach undeniably has and will continue to contribute to the development of the profession in this field in an important way. At the same time, this approach perpetuates the tendency in occupational therapy to theorise about one's self and the potential for our own profession, rather than communicating outwards beyond the profession (Cooper, 2012). Secondly, but closely related, the dominant voice exploring the role and potential of occupational therapy with refugees is the voice of the occupational therapist itself. Gerlach (2015), calls for occupational therapists to adapt a co-construction approach in order to counter these patterns, especially

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[1]Recognizing the complexity in terminology in human migration this article adopts the term refugees. This term was utilized by my co-authors as an all-encompassing term which includes individuals still in the process of applying for asylum, those who have refugee status, and those who are citizens of a country which they at one point came to as a refugee. The authors would like to state that this is not meant to homogenize a group which embodies a large range of diversity in individuals and sub-groups, and that this complexity needs to be acknowledged when working in this field.

when working with groups who have been considered as marginalised. Currently, refugees themselves have been largely left out of the conversation.

In an attempt to provide refugees with a platform to join this conversation, a workshop was created where four individuals with a refugee background and one occupational therapist engaged in a discussion. The aim of this workshop was to explore what occupational therapy was – through the eyes of the individuals with a refugee background, what role occupational therapy could have with refugees and what the profession of occupational therapy needs to do in order to take on this role.

Method

Four refugees, each from a different country of origin, each with a different academic background and each living in the Netherlands for a different amount of time (ranging from 18 months to 20 years), were invited for a workshop at the Amsterdam University of Applied Sciences (AUAS). The individuals were invited through personal contacts of the first author and through programmes which support refugee students and researchers. Individuals could volunteer to participate in the workshop and were offered the opportunity, if they chose, to collaboratively write an article on the results. Four people participated in the workshop and these people will from here on be referred to as the co-authors. Recognising the safety issues that is a reality of the life of some of the co-authors, consent to have the authors name published was gathered from all co-author participants prior to starting the workshop and submitting the paper. At any moment the co-authors could decide to not have their name published or to use an alias. All interviews and discussions were conducted in Dutch, and participants could speak English or their native language that other co-authors understood, in order to explain themselves. All results were eventually translated into English by the first author, checking with the other authors that the translation was accurate.

Some of the co-authors had experiences with occupational therapy in the past, personally or professionally, while others had never heard of the profession. The co-authors received a one-page handout about occupational therapy through email prior to the workshop, and were encouraged to explore information themselves online. On the workshop day, the co-authors created an interview guide and interviewed three occupational therapists, all currently working at the AUAS with a variety of previous professional experiences. The co-authors conducted interviews in order to answer the following questions, which were pre-defined by the occupational therapist author.

(1) What is occupational therapy? (As defined by the co-authors themselves)
(2) What role can occupational therapy have with refugees?
(3) What is needed in the profession in order to take on this role?

Following the interviews, the exploration of results started by creating a wordcloud of words that the co-authors felt they would use to describe occupational therapy. From these words, a further group discussion of the interviews was used in order to answer the above-listed questions. Answers were written and collected on flip-over papers by the co-authors with a refugee background, and then were written out in English by the first author using the headings below. Drafts of this paper were shared amongst the co-authors for revisions.

Who is we?

This paper is a collaborative effort written by four individuals with a refugee background and an occupational therapist. We decided to use the word *we* and *I* throughout the paper. *We* is used firstly, to represent that we as a group of five individuals have presented this paper as a combined message to the occupational therapy community and beyond. More specifically, when the word *We* is used in the following sections entitled: *What is occupational therapy, What role can occupational therapy have with refugees and What does occupational therapy need to do to respond* it is used to represent solely the combined voice of those co-authors with a refugee background. The discussion section which then follows, is a reflection on this story through the view of the co-author who is an occupational therapist.

Results

What is occupational therapy?

To answer this question we created a wordcloud and definition of occupational therapy based on our previous knowledge, combined with the information gained through the interviews. The wordcloud can be seen in Figure 1 (translated from the original wordcloud which was in Dutch). This wordcloud was then used to create the definition of occupational therapy presented at the beginning of this paper.

What role can occupational therapy have with refugees?

We identified specific roles which occupational therapy could adopt in the lives of refugees. To begin, we identified that refugees require the same access to care services that any other citizen receives. Refugees need not only basic healthcare, but also rehabilitative care to manage physical and psychological issues. One of our co-authors experienced this first hand. On arrival

Figure 1. Wordcloud created by co-authors with a refugee background on words that describe occupational therapy.

in the Netherlands, this author's mother had physical health issues which limited her mobility, confining her to bed. Though her immediate health concerns were addressed to reduce pain and encourage healing, this being included in the basic healthcare for asylum seekers in the Netherlands, this author's mother was not provided with rehabilitation or strategies to facilitate mobility and independent self-care. This author and her siblings were left to assist with the basic activities. We feel that occupational therapists, and other allied health professionals, should be involved in the health provision for individuals located in refugee centres, just as they are with other citizens.

Aside from the physical needs, the majority of the discussion we had was about the potential roles occupational therapy could adopt in working with refugees to assist with integration into their new communities and society.

Be a translator

We feel that occupational therapists have the potential to adopt the role of translator, not a translator of language, but one of culture and society. Refugees are often missing information and experience with the simple day-to-day activities which are the building blocks for participation in society. By missing these simple activities, or by performing them in a way which does not 'fit' with the locals, we often unintentionally create distance between ourselves and the native citizens of the country where we now live, which creates exclusion. The occupational therapist, as an expert in day-to-day activities, can act as a translator; collaboratively identifying, coaching and providing training in these simple tasks, which could be considered a spring-board to greater participation. The experience of one of our co-authors explains how important these simple tasks can be for newcomers. She shared with us the experience of having to adapt to the biking culture in the Netherlands. This skill, in her home country reserved for leisure or sport, became a necessity for daily life. Not only was it assumed she would use a bicycle as daily transportation for herself to work, but it was also assumed she would use it as a mode of transportation for her children. No one ever explained how to transport children on the bicycle and when the children experienced the normal childhood injuries, associated with childhood bike mishaps, no one also explained that this was a normal part of childhood in the Netherlands. The assumption of native Dutch people that she knew how to use the bike as a family mode of transportation and would embrace this, was never fully explained or explored, leaving her feeling alienated.

We feel that this role of a translator, just as any translator would do when bridging two individuals who speak two different languages, must go two ways. Individuals present in the settings where refugees will work, play, study and live also should be the focus of any occupational therapist wanting to work with refugees. The occupational therapist can translate the perspectives, norms, history, strengths and challenges of the refugees, to those they will come in contact with, if the refugee is unable to do this him/herself. This can be in examples such as the school teacher of a refugee child, a boss of a refugee entering the workplace or a community where a new refugee settlement site will be placed. If the occupational therapist focuses only on the refugee, and neglects to work with the people they will come in contact with, then the occupational therapist misses half of the equation.

Be a matchmaker

We feel there is also a unique role for occupational therapists to play in matching refugees to new

opportunities in their new settings. Recognising the strengths and experiences that refugees have is important and identifying these specific past skills helps to begin to establish links to these in new settings. As a profession that claims to focus not only on problems, but also on people's skills, occupational therapists could help in this area. There are two ways this can be done. Firstly, on a one-on-one basis, occupational therapists can individually coach and guide refugees to identifying their skills and from there exploring opportunities to apply them again. Beyond that, occupational therapists can advocate to a larger audience, for proper higher degree recognition of refugees arriving in a new setting. We as co-authors used the term 'professional deprivation' during our workshop, as a concept which we used to explain people working in jobs below their skills and education level, lacking the opportunities to reach their 'past level'. We feel this can be mentally devastating for newcomers. Helping people match their skills to appropriate work roles, and advocating for other's to recognise these can be a role for occupational therapy.

Be a connector

Lastly, we feel there is an important role for the occupational therapist to be a connector. This also takes many forms. Firstly, the connector role is one of bringing refugees together. In this, the occupational therapist has to do no more than to provide a place where refugees who have lived a long time in a new country can meet with those who have just arrived. Even we ourselves, through participating in the workshop and writing this article, experienced moments where we saw ourselves in the stories of the other co-authors. Those who had been here longer were able to relate to the situations of those of us who were more newly arrived refugees, which was a comforting thing for the newcomers. This role of the connector is one of providing spaces for peer support.

Additionally, we spoke of the role for the occupational therapist to become a connector in an attempt to advocate for the daily participation of refugees. If occupational therapists can connect to local, national and international organisations working with refugees, they can start to connect the programming being done there to the adjustments needed in the day-to-day lives of the refugees, bringing in the role of translator as described above.

What is needed from the profession in order to work with refugees?

In our opinion, there are important things occupational therapists and the occupational therapy profession need to embrace in order to work with refugees.

Be careful what you ask for

Occupational therapists must understand the rules and the systems that displaced persons find themselves in. During the workshop, we discussed this using the example of motivation. We have all been asked by someone: 'What do you want in the future?' or even 'What is your goal?'. Occupational therapists need to understand that by asking this they could potentially be asking someone an impossible question. Refugees often find themselves in a place of uncertainty due to the asylum systems of the governments they are in, uncertain whether one can stay in the country they are in, for how long, or what the new life in this country will look like. In this place of uncertainty, thinking and looking towards the future is not practical, nor safe, nor a priority. First basic needs of rest, health and legal confirmation of asylum status and residency are needed before any further goal setting can occur. Often, refugees are hesitant and often even unable to answer the question 'what is your goal?' or answer it with the honest answer of 'getting my papers', as this is truthfully the biggest priority at that moment. Not stating a clear goal or plan for the future is often viewed by others as being unmotivated, that refugees are not willing to work towards integration in a new setting. We think that this motivation will come, but only once certainty is in place. Upon arrival, the situation we left behind is still too raw to even allow ourselves to be able to think anything else than being safe and remaining safe. As an occupational therapist, you need to understand that individuals who don't verbalise goals may not be unmotivated, but instead may be in a position where they have no choice, or don't feel secure or able to set goals. We summarise this by saying: you may be asking someone what they want to do, in a system that actually encourages people to wait and do nothing.

Step out of your box

In order to take on the role of occupational therapists with people with a refugee background, you need to take a step outside of the box in which you, and the profession, are used to living and working in. Assuming that refugee customs and family roles are the same as yours could lead to inappropriate interventions and complication of relationships. As an example, we draw again on the experience of one of our co-authors who shared the story of her mother and her need for healthcare earlier in this piece. She explained that in this situation, her dad was living with her mother. When her mother was in need of care to dress and wash herself, as an occupational therapist coming from a western culture, you could assume that the husband could provide the care. There is a danger of assuming that the roles in the family are the same for refugees as they are for you. The father, though home, was in no way expected to provide any kind of

personal care to the mother. This would have been inappropriate. Here it was the expectation that the daughters would fulfil this caregiving role. If an occupational therapist fails to recognise this, or attempts to force individuals into other roles without an open discussion on role expectations, then this can result in negative feelings from the refugee and the refugee's family.

Making a new you

As occupational therapists you need to consider the unique situation refugees find themselves in. The experience of assuming the identity of 'refugee' is not something that goes away once papers are received. We describe it as a sticker, a sticker which you continue to fight with and against for the rest of your life. This sticker influences everything people as refugees do, how we think, work, study, play and relax. Essentially you are creating a new 'you' – a process that can only begin once you feel safe and have the space and safety to do so, but which continues throughout your entire life.

Saying this, occupational therapists should consider how this can also be a strength for the profession. By having occupational therapists who have experienced themselves what it is to have this sticker, and can understand it when they see it in the daily choices and actions of others, can only be considered a strength for the profession. Recognising this, refugees often are unfamiliar with this profession and so actively recruiting people with a refugee background to meet and in turn perhaps study occupational therapy, could in the long-term benefit the work of occupational therapy with refugees.

Discussion

As an occupational therapist who engages in research from perspectives of critical theories in occupational science there are a few items which are striking to me in the results and advice of my co-authors presented above.

Firstly, in occupational therapy practice and research today, a dominant discourse still persisting and informing interventions and theories is that of a medical discourse, stemming from positivist paradigms focused on physical functioning, illness and disability (Laliberte Rudman, 2018). A simple google dictionary search provides me with the definition of occupational therapy as 'the use of particular activities as an aid to recuperation from physical or mental illness'. The definition provided on the website of the American Occupational Therapy Association states: 'Occupational therapy practitioners enable people of all ages to live life to its fullest by helping them promote health, and prevent – or live better with – injury, illness, or disability' (AOTA, 2018). These definitions, using words like 'recuperation', 'illness' and 'disability' maintain a discourse of a profession focused on the individual, the body and the return to 'normal' functioning.

As I reflect on the definition and wordcloud created by my co-authors, it is striking that this notion of physical functioning, illness and the body are not the main focus of the definition, nor their vision for the end goal of the work of the profession. Instead the end goal of the profession, as defined by my co-authors, is identifying issues in, and finding strategies toward, *societal participation*. The call to broaden the discourse of occupational therapy to beyond just physical functioning has been presented numerous times in literature (Dickie et al., 2006; Gerlach, 2015; Phelan, 2011; Whalley Hammell, 2015). Despite this, the focus on illness and biomedical interventions in our profession continues to push occupational therapists to focus on the individual and their dysfunctions. As described by Whalley Hammell (2015, p. 5):

> As researchers, we have demonstrated a commendable commitment to developing and validating a plethora of assessments that test the specifics of individuals' dysfunctions – from nystagmus to ideational praxis – but significantly less commitment to assessing and addressing those socially structured inequalities that disadvantage and disable populations of people … .

Adding to this are the words of Phelan (2011, p. 169), when she states:

> Although occupational therapists consider the person, occupation, and environment in context and are open to making adaptations in all realms, therapists are often asked to focus on the person and his or her impairment, secondary to the demands of health care settings that prioritize the biomedical model.

The definitions and recommendations presented by my co-authors, are in my opinion a presentation of their hope for occupational therapy. I am left to question whether our justice-based profession, will be able to truly 'do justice' to the needs and hopes of groups such as refugees if it continues to align with the medical model and illness discourse.

Additionally striking in reading the results of my co-authors, is the clear advice, or even warning to take time to question and be aware of assumptions.

The first time this warning is presented is in the story about motivation. What is central to this story, is that when refugees are asked what their goals are, and they do not choose, then they can be viewed as unmotivated. The assumptions seen here are regularly criticised in occupational therapy and occupational science literature; the assumption that everyone has choice and *can* choose (Galvaan, 2015; Johnson & Bagatell, 2017; Whalley Hammell, 2009). Assuming self-determination ignores the institutional and social structures which limit choice. This is reflected in my co-authors

statement of: 'you may be asking someone what they want to do, in a system that actually encourages people to wait and do nothing'. 'Encourages' being in this case not verbal directions per se, but indirect messages embedded in policies and procedures.

This perspective was explored in May 2018, during the WFOT conference in Cape Town, South Africa keynote lecture of Karen Whalley Hammell, when she explained that the assumed capability to choose is presented as almost common sense in occupational therapy practice models, but are reflections of the neo-liberal and middle-class notions which dominant theories. She states: 'As if choice is simply a consequence of individual volition, this is a uniquely privileged assumption' (2018). This perspective was also introduced in work by Galvaan (2015), examining how occupational choice in adolescents in South Africa is shaped by internationalisation of the structures in which they exist and presented in Laliberte Rudman's concept of occupational possibilities: ' … what people take for granted as what they can and should do, and the occupations that are supported and promoted by various aspects of the broader systems and structures in which their lives are lived' (2010).

Occupational therapists who fail to recognise the constraints on choice for refugees display ignorance to the reality of refugees. Seeing those who seem to 'fail' to choose as 'unmotivated', can be damaging and can create negative emotions amongst the refugees. Maintaining our occupational therapy focus on the individual, and seeing them as unmotivated, continues to strengthen the medical and illness-based focus, blaming person-specific factors as the causes of diminished function, instead of looking to the systems which surround them (Laliberte Rudman, 2013).

The second warning of the dangers of assuming can be seen in the story of the assumptions in caregiver roles. Occupational therapists must be comfortable to question the assumptions which are culturally embedded in their worldview and in their practice. Whalley Hammell also warned against this in her WFOT keynote when she stated: 'When dominant groups fail to recognize their perspectives as "perspectives" they view their experiences, values & perspectives as universal, as neutral and objective' (2018). Connecting back to what was explained in the introduction, by placing only the occupational therapy voice in the centre of the discussion on the role for occupational therapy with refugees, we are continuing to fail to recognise that our perspectives on this role with refugees is not universal, but just one perspective of potentially many. Questioning these assumptions is not new in occupational therapy, but what is new in this piece is that this call to question is not theorised by occupational therapists but by refugees themselves.

A third interesting point of reflection is the many moments that the role for occupational therapists as advocate arose during the discussions of the co-authors. Often my co-authors were not identifying the needs of direct service provision, but instead were asking for an advocate, or a platform for refugees to address the issues they experience in their day-to-day life. Terms developed by my co-authors such as 'professional deprivation', an obvious link to the occupational deprivation that is embraced in occupational therapy theory on this topic (Whiteford, 2000), shows the power of the potential and the shared concern for, lack of meaningful engagement. The role of an advocate, as identified in the roles of communicator, connector and matchmaker, show a need for a companion in addressing the institutional, political and social structures that are impacting on participation.

Conclusion

This experience has provided a platform for individuals with a refugee background to join the discussion on occupational therapy with refugees, a platform which was eagerly and critically accepted by the group. These results are the opinions of four refugees, after discussions with a few occupational therapists. It is dangerous to say that this is a homogenous voice or answer for all refugees, nor for all occupational therapists. What this article does provide is a starting point. Moving forward, occupational therapists should continue to develop spaces for co-exploration of the needs of refugees and our role in meeting these needs. These spaces should also be open to other professionals, drawing on other expertise and theoretical foundations. Through these discussions, it is important to continue to explore the assumptions and practices of power in the occupational therapy profession. This is a process which can be uncomfortable or painful, but critically necessary in order to avoid interventions guided by ignorance and assumptions. This process requires a careful and respectful dance. As refugees take a step forward towards new lives, occupational therapists potentially have the privilege to move forward with them. But, in order to move forward, occupational therapists must also take a critical step back, reflecting on and recognising assumptions that they have and how these assumptions influence the lives of those with whom they aim to work.

Disclosure statement

No potential conflict of interest was reported by the authors.

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