WFOT
World Federation of
Occupational Therapists

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OCCUPATIONAL THERAPY PRACTICE AROUND THE GLOBE

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Kit Sinclair
Editor

Editorial

This month the WFOT Bulletin is in English and Spanish. Once again sincere thanks go to my Spanish speaking co-editors for their promotion and support of the peer review process and their gathering of theme-based manuscripts. Carmen Forn de Zita in Venezuela and Margarita Ganzalez in Colombia present a formidable team, joined this issue by Carolina Alchouron in Argentina.

And on the subject of editors, I would like to congratulate one of the longest serving editors in the occupational therapy global community, Upma Barnett, on her 30 years of contribution as editor to the British Journal of Occupational Therapy (BJOT). Her work spanned an enormous period of change for the profession in the UK as pre-registration training moved from diploma to degree, post graduate degrees became commonplace and doctors and professors were no longer headline news. BJOT's first Impact Factor rating, expected this summer, will come as acknowledgement of her commitment.

Our theme this month, working with families, has captured a variety of issues that are integral to occupational therapy philosophy and practice. Though family life may take different forms in different societies and cultures, they are a crucial support for human health and well being. What could replace the occupations of child-rearing, bread-winning and home-keeping? Though the modern world is characterized by generational changes in lifestyle and mobility, the family remains a constant in society, usually offering security, protection and solidarity in a world which may seem uncaring. For occupational therapists working with individuals who have been affected by sometimes devastating change, families can offer a crucial link.

The articles in the present issue emphasize the interconnecting relationships, support and affirmation that provide a secure base for families to provide that crucial support for people affected by dysfunction or disability. They also note the advantage for families of connecting with the wider community.

There are certain universal perspectives of occupation in working with people of all ages and cultural groups. They include the need to understand the everyday perspective, that is, 'a day in the life' of the persons involved, e.g. client, family member, caregiver, and their own perceived roles and responsibilities. More and more, these perspectives also include the necessity to understand working with people of low economic means, promoting quality of life, social protection, education in health, and supporting families in seeking equal rights.

These perspectives require creativity on the part of the occupational therapist (see Jahagirdar in this issue), interconnectedness, shared decision making and the use of local, culturally appropriate approaches, communication, tools and materials. Working with families involves recognizing client capabilities and aspirations, as well as family expectations and dynamics within cultural-social environments. Occupational therapists need to be aware of the changing circumstances within the family on a day-to-day basis and provide the support necessary for family members to find solutions to everyday issues (see Burllău in this issue). Occupational therapists can support the holistic development of families and dignity of the population (see Pacheco and Pereyra). Family-centred educational approaches are supported in the article by Hahn and DeRuiter, as well as in the suggestions brought up by a family member in Burllău's article.

Occupational therapists should be supporting caregivers to help their family members with dementia to be engaged in daily activities and to have a sense of self and autonomy, despite the family member's progressive decline in cognitive function (see Chung in this issue).

Client and family members' access to information is an important evolution in health care which occupational therapists are taking advantage of. The health care practitioner no longer lives in a 'yes, doctor' world. We can support and enhance families' ability to find solutions to everyday problems and to work toward aspirations for themselves and their members. Through this process, we support clients to achieve greater quality of life through family support and, in some situations, to take more control of their own lives, such as adolescents with chronic illness transitioning into self management (see Versnel, in this issue).

The Inaugural WFOT Lectureship will be a new feature of the WFOT Congress 2014. Think about the occupational therapist you would like to receive this great honour. Access the nomination form in the resource center at www.wfot.org

Ritchard Ledgerd
(WFOT PCo Promotion and Development)

WFOT Report
World Occupational Therapy Day 2012

Introduction

The third annual event aimed at celebrating the global profile of the profession took place on the 27th October 2012. World Occupational Therapy Day was launched in 2010 and has continued to generate interest from around the world from occupational therapists, assistants, students and the general public. This report outlines some of the reports that were received from individuals, groups and WFOT Member Organisations and how they contributed to making this a highly successful event. The report concludes with the results from a short feedback questionnaire circulated at the end of World Occupational Therapy Day.

WFOT Resources

WFOT negotiated sponsorship from *Athona Allied Health Recruitment* to provide a number of resources to support the World Occupational Therapy Day initiative; these included 2012 Logo, Facebook cover art images, posters, desktop calendars, pic badges for social networking, in addition to a Guide to World Occupational Therapy Day publication and reference to other WFOT published materials.

WFOT also worked in partnership with three other organisations to produce mutually supported and co-branded events to celebrate World Occupational Therapy Day. The OT Global Day of Service (OTGDS) was coordinated by *promotingot.org* and encouraged occupational therapists, assistants and students to volunteer their free time on the 27th October to support local community initiatives. WFOT worked with publisher *Wiley*, to provide a free edition of the publication "Occupational Therapy International" in addition to discounted subscriptions for WFOT Individual Members. WFOT worked with *Your World Healthcare Recruitment* to develop a photography competition, launched at the end of World Occupational Therapy Day and due to conclude in May 2013.

Celebrations – open days, presentations and promotional events

There were many creative displays and events organised to celebrate World Occupational Therapy Day 2012. WFOT received feedback from all around world with how they organised open days, presentations and promotional events in their countries and regions. Some hosted open days in their occupational therapy department's inviting colleagues and the general public to learn more about the profession. Others organised exhibitions, conferences and seminars in countries including India, Turkey, Kenya, Mauritius, Canary Islands and Jordan.

Some WFOT Member Organisations held national OT week celebrations during the week of 27th October. In France, the national theme for 2012 was 'accessibility for all', and local events such as exhibitions of pictures were planned. In Kenya, this year's theme was 'Enhancing Safe Driving for a Safer Nation'.

Some countries and facilities combined celebrations – the Seth G.S. Medical College & K.E.M. Hospital, Mumbai, India, combined the celebration of the 62nd Foundation Day of the school, with World Occupational Therapy Day celebrations on 26th October.

Norwegian students organised events in shopping malls and streets connected to their education institutions. Students provided information about the profession and the public had the opportunity to try out different occupational therapy related activities. Students in Alberta, Canada were involved in an innovative poster design competition to raise awareness about occupational deprivation and justice. In Mauritius, the celebrations extended to a beach party enjoyed by students and practitioners.

Print media picked up stories of World OT Day happenings in many countries including India and Singapore.

Website and social media promotion

WFOT's social media page on Facebook www.facebook.com/wfot.org continued to attract interest with over 1000 new supporters generated in just over a month. Messages of support from people and organisations in 25 countries were received from one post alone. WFOT received feedback about some of the online events that took place to celebrate World Occupational Therapy Day including;

National Association websites

Many WFOT Member Organisations told us about changes to their websites that had been made to support the event, including Greece, Romania, Germany and the UK.

OT4OT – 24 hour Virtual Exchange

For the third year running, OT4OT hosted the free 24 hour virtual exchange – one hour presentations by different speakers from all over the world in English and Spanish. The event was kindly supported by the University of the Sunshine Coast, Australia. For more information the event and speakers visit http://ot4ot.com/ot24vx2012/

Carnival Blog

Linda Harrison sponsored the second annual Blog Carnival celebrating World OT Day. OT bloggers from all over the world submitted posts on the theme of “Exploring Balance”. The posts presented many personal stories about the challenge of keeping balance in the many roles in our lives http://www.lindasdailylivingskills.com

Twitter Event

The #OTalk team ran a Twitter event on the theme of encouraging OTs to think about the role OT can have in public health. The aim was for people to share resources on this topic by writing blogs, and stimulate a discussion from a global perspective. https://www.facebook.com/events/337729209644143/

OT Quiz App

The University of Salford (UK) developed the ‘OccuBuzz’ app. Participants responded to seven fun quiz questions, and received helpful tips and links at the end. Available online at http://www.occubuzz.com

Live Podcast “Celebrating the Occupational Therapy Global Family”

On Saturday October 20th, 2012, Armando Sanchez hosted a live podcast from the blogtalkradio Los Angeles, California studio. The event was co-hosted and moderated by Terry Olivas-De La and included speakers from all over the world. Available online http://www.blogtalkradio.com/latino-role-models-success/2012/10/20/celebrating-the-occupational-therapy-global-family-live

Wiley Publishing

A free issue of Occupational Therapy International, and WFOT Individual Member discounts on subscriptions were made available from Wiley. The Occupational Therapy International publication offered a free virtual issue in celebration of World Occupational Therapy Day 2012. This topic for this issue was ‘Stroke and Occupational Therapy’. Available at http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1557-0703/homepage/virtual_issue__stroke.htm

Wiley also launched discounted subscription for WFOT Individual Members to the publication Occupational Therapy International available at http://ordering.onlinelibrary.wiley.com/subs.asp?ref=1557-0703&doi=10.1002%2F%28ISSN%291557-0703

Wiley are also offering a 20% discounted rate off Occupational Therapy books published by Wiley. For more information, go to http://onlinelibrary.wiley.com/subject/code/000115/homepage/for_wfot_members.htm

OT Global Day of Service

Occupational therapists, occupational therapy assistants, and students from 32 countries participated in the second Occupational Therapy Global Day of Service (OTGDS) on October 27th, 2012 in honour of World Occupational Therapy Day.

Thousands of participants worked with multiple colleagues or groups of students and volunteered in a variety of settings. Some examples include, presentations, lectures, information sessions all aimed to teach members of the community the importance of occupational therapy, voluntary service and treatment for individuals within the community who require occupational therapy services, events geared toward educating individuals with disabilities and their families about ways to accomplish potentially challenging tasks. For more information www.promotingot.org

World Occupational Therapy Day – Questionnaire Feedback

WFOT hosted an online survey aimed at generating feedback about World Occupational Therapy Day 2012. The survey was available from the 27th October 2012 until 29th January 2013 via a dedicated URL https://www.surveymonkey.com/s/WOTD2012. The survey link was distributed to WFOT Member Organisations and posted on the WFOT website and Facebook page.

Responses

129 people started the survey and 99 people completed it (79%). The majority of responses were provided by individuals 71 (71%), 15 (51%) replying on behalf of WFOT Member Organisations, 7 (7%) replying on behalf of a groups of occupational therapists, 4 (4%) on behalf of an organisation and 2 (2%) other. 57 (58%) of respondents stated they regularly accessed information about World Occupational Therapy Day in the months and weeks leading up to the event.

Primary sources of information

Table 1 shows the primary source of information that respondents used to gain information about the materials and events being promoted for World Occupational Therapy Day. WFOT's resources accounted for 84% of responses with the primary information source being its Facebook page.

Table 1. Primary location for sourcing information about World Occupational Therapy Day

Information Source	Responses (n = 99) n %
WFOT Facebook page	45 (45%)
WFOT website	23 (23%)
Other organisations website, Facebook page, blog, publication	7 (7%)
National Association – Facebook page	4 (4%)
Referred by a friend/colleague – email	4 (4%)
WFOT e-newsletter	3 (3%)
WFOT – other communication	3 (3%)
National Association – website	3 (3%)
National Association – other communication	2 (2%)
Workplace/University – other communication	2 (2%)
Referred by a friend/colleague – Facebook page	2 (2%)
National Association – publication	1 (1%)

WFOT World Occupational Therapy Day materials

WFOT produced a range of resources to enable the promotion of World Occupational Therapy Day 2012. The materials produced were available in digital formats and available to download from its website or its partner's website. Table 2 shows the materials most used by respondents to promote World Occupational Therapy Day 2012.

Table 2. Showing the most used materials produced by WFOT for World Occupational Therapy Day 2012

WFOT Materials	Responses (n = 75) n %
World Occupational Therapy Day logo	40 (53%)
World Occupational Therapy Day posters (free)	31 (41%)
World Occupational Therapy Day cover art for Facebook	20 (27%)
Guide to World Occupational Therapy Day document	16 (21%)
WFOT 60th Anniversary poster (free)	16 (21%)
World Occupational Therapy Day picbadges	13 (17%)
WFOT Definitions of occupational therapy document	12 (16%)
WFOT Position Statements	10 (13%)
Occupational Therapy Global Day of Service (OTGDS)	7 (9%)
World Occupational Therapy Day desktop calendars	6 (8%)
Occupational Therapy International journal (sample copy)	6 (8%)
WFOT Human Resources Project 2012	6 (8%)
World Occupational Therapy Day Photo Competition information	5 (7%)
WFOT Information Package	4 (5%)
Other (please specify)	3 (3%)
WFOT Posters ($40/$20)	2 (2%)

The World Occupational Therapy Day logo was the most used resource provided by WFOT (53%), in addition to posters (41%). The least used resources were posters which required payment (2%).

Ratings of World Occupational Therapy Day materials

Table 3 shows how respondents rated the materials supplied by WFOT for World Occupational Therapy Day. 87 (86%) of respondents rated the materials as good or excellent.

Table 3. Respondents rated the materials supplied by WFOT for World Occupational Therapy Day

Ratings of WFOT Materials	Responses (n = 96) n %
Excellent	32 (33%)
Good	55 (53%)
Average	10 (10%)
Poor	1 (1%)
Very Poor	0 (0%)

Promotional Methods

Respondents were asked to state how they celebrated the event and provide examples of what they did. A thematic analysis of the responses was undertaken and generated into the themes shown in Table 4.

Table 4. Showing how respondents promoted World Occupational Therapy Day

Promotional methods	Responses (n = 42) n %
Attended or arranged a promotional event	22 (52%)
Facebook (changed profile images, posted and promoted to friends)	15 (36%)
WFOT Picbadge	6 (14%)
Website/Blog/Podcast	4 (10%)
Attended OT4OT 24 Virtual Exchange	3 (7%)
Twitter/SMS/Email	3 (7%)
Published or developed promotional materials	2 (5%)
Lobbying	1 (2%)
Other	4 (10%)

Over half of respondents attended or arranged promotional events (52%). The use of social media, particularly Facebook was the second most commonly used activity (36%). It is interesting to note the use of digital and online promotional methods that were listed in all the other responses.

WFOT Resources – Future Development

Respondents were asked to state if they had any ideas for future resources and promotional materials that could be developed by WFOT for World Occupational Therapy Day 2013. A thematic analysis of the responses was undertaken and generated in to the themes shown in Table 5.

Table 5. Showing suggestions of future resources that could be developed by WFOT for World Occupational Therapy Day

Future WFOT resources	Responses (n = 25) n %
Online Forums	6 (24%)
Promotional Items	6 (24%)
Posters	4 (16%)
TV Adverts and Videos	3 (12%)
Include date on World OT Day logo	2 (8%)
None Needed	2 (8%)
Other	4 (16%)

Online forums were cited in different ways with suggestions of developing “a student area”, reintroducing the Occupational Therapy International Outreach Network (OTION) “bring back OTION” in addition to being able to work collaboratively on WFOT projects. Promotional items included stickers, key rings, badges, pens, calendars and leaflets. Other examples included suggesting one particular type of activity that will be performed worldwide.

Conclusion

World Occupational Therapy Day continues to attract interest and participation from occupational therapists, assistants and student worldwide. This report features some of the feedback shared provided by individuals and organisations in addition to those who responded to the questionnaire. Although the number of responses to the questionnaire is small, it provides a baseline to measure future activity and development of the event. The use of online media to celebrate and support World Occupational Therapy Day is recognised as important method to promote the global profile of our profession. WFOT is an organisation primarily managed and staffed by volunteers with limited financial resources; however the support and value placed on World Occupational Therapy Day based on the feedback received, suggests continued investment should be maintained to develop the event.

Acknowledgements

Thanks go to Jenny Pascoe, WFOT Executive Assistant for her assistance in collating and editing feedback from reports submitted to WFOT. Thanks also go to all the active participants of World Occupational Therapy Day throughout the world for their ongoing support to the Promotion and Development Programme objectives.

2012
WORLD OCCUPATIONAL
THERAPY DAY

Professionals partnering with family carers in home-based activity for those with dementia

Pat Chung
(United Kingdom)

Abstract: *Past research into family caregiving activities tended to focus on general aspects of caring (looking after) rather than on engagement of a relative in activities. If professionals are to work in partnership with carers to deliver a home-based activity programme for those with dementia in a person-centred manner, it is crucial that they have an understanding of the process in which the activity needs of people with dementia are being met by home carers. The purpose of this article is to report on how co-resident carers, through engaging their relative, enhance their relative's autonomy and a sense of self, despite a progressive decline in cognitive function. The findings of the study bring a deeper insight into this process. Such insight is essential for practitioners if they are to identify and develop more realistic intervention strategy, one which will work in effective partnership with and support of family carers, using a person-centred approach.*

Key words: Person-centred care, caregiving, dementia, activity engagement.

Introduction

Dementia is now high on the public health agenda in many countries with the aim of advocating the development of programmes which, through promoting independence and encouraging activity, optimise the well-being and quality of life of those living with dementia for as long as possible (Department of Health/DH 2012, World Health Organisation/WHO 2012). These programmes are often influenced by a person-centred approach which aims at enabling and empowering both the people with dementia, and their families in the community, to live well with dementia, and have control of their own daily care management. The long-term goal is to reduce the number of people admitted to care prematurely resulting from lacking of appropriate support (DH 2012, Alzheimer's Society/AS 2009). If true person-centred community-based care for people with dementia is to become a reality, carers need to be supported in their role. Moreover, such an approach requires health and social care practitioners to work in partnership with family carers to promote their relative's autonomy and sense of self. This has an implication for occupational therapy practice because the fundamental belief of occupational therapy is rooted in the assumption that humans have an 'innate need to engage in occupation' (Wilcock 2001, p. 5). Through engagement in meaningful activity, an individual can express who he or she is and so maintain a sense of identity (Christiansen 2004).

Person-centred approach

The term 'person-centred care' is associated with a wish to position persons with dementia at the centre of holistic care by understanding their subjective experiences, and how such experiences are influenced by their social-cultural environment (WHO 2012, AS 2009, National Care Forum 2007). A key aspect of this approach is recognition of the fact that the person still has a self. This idea has been advocated by many scholars including the late Tom Kitwood who contended that individuals with dementia have the potential to present the self within a nurturing environment, despite cognitive decline (Kitwood 1998). Kitwood (1995) viewed dementia as a disability, suggesting that how a person is affected depends crucially on the quality of care. When quality of care is poor, it was often associated with "malignant social psychology" (MSP). Aspects of MSP may include being disempowered, intimidated or treated like a child (Kitwood 1990). Kitwood argued that when a person has been subjected to MSP for an extended duration, his/her self-esteem is damaged. Hence, the most disabling effects of dementia are the threats to a sense of self and to one's identity (Kitwood and Bredin 1992). This approach held that problems of the person with dementia (e.g. apathy, wandering and agitation) are not to be considered inevitable in the process of dementia; rather, they can be manifested and made worse by external factors (Balwin and Capstick 2007). A similar view has been expressed by researchers such as Sabat (2001, 2006), who suggests that the 'socially presented selves, or personae' of the persons with dementia become vulnerable (2001, p. 294) because this aspect of the self (social identity) is often dependent on the support of others. Hence, the interpersonal relationship between people with dementia and others (e.g. carers) can both positively and negatively impact on the quality of care; thus a key element within a domestic environment is the family carer.

Many countries, including the United Kingdom (UK), now adopt the person-centred approach to the management of the behaviour and psychological difficulties of people with dementia (AS 2011, NICE 2006). The UK government promotes the use of non-pharmacological therapy (including activity-based intervention) as the first line of intervention for cognitive, behavioural and psychological dementia symptoms (NICE 2006). This results from acknowledging that side-effects of pharmacological treatment can be harmful to the person involved; and from an increasing positive belief that people with dementia can be enabled to live a better quality of life by engaging in meaningful activities (DH 2010, AS 2011). Family carers, like health and social practitioners, are therefore encouraged to support their relative so as to continue their daily activities as long as possible. Engagement in meaningful occupation is closely associated with maintenance of health and well-being (Wilcock 1995, 1998, 2001).

Family carers have a vital role to play in supporting those with dementia in everyday routine activities but even this often presents carers with a challenge. Carers are at high risk of mental health problems and psychological distress (Bertrand et al 2006, Brodaty 2009, Yaron et al 2011). Nevertheless, it is important to note that research into support and intervention for carers has highlighted that informal carers are unlikely to utilise such services unless they perceive services filling a need that carers have already identified for themselves (Zarit and Leitsch 2001, Brodaty et al 2005).

Past research into family caregiving activities tended to focus on general aspects of caring (looking after) rather than on engagement of a relative in activities. The purpose of this article is to discuss how co-resident carers, through engaging their relative, enhance their relative's autonomy and a sense of self, despite a progressive decline in cognitive function. The article is based on the findings of a larger study which aimed to explore carers' perception of how they make decisions concerning their engagement with their relative in everyday activities at home, during the caregiving journey.

Method

In the larger study, in-depth qualitative interviews were carried out with co-resident carers in two stages; firstly individual interviews with fifteen participants and then in stage two focus groups with twenty-one participants. For both stages, research approval was obtained from respective Research and Development Unit and Local Ethics Committee. Invitation letters were sent to potential participants through gatekeepers.

The first stage aimed to gain an understanding of the carers' experiences of involving their relative with dementia in activities which they perceived to be 'beneficial' for them. Interviews were conducted to allow the participants to co-create an agenda with them to respond more fully and to allow the researcher to gain a greater flexibility in interacting with the participants (Gillham 2005). Details of the first phase were published elsewhere (Chung et al 2008). In the second stage, the overall aim was to seek participants' views about the emerging findings from stage one and to refine the key categories. Five focus groups were carried out in order to allow the researcher to collect and generate rich data (Fontana and Frey 2008) from a number of people in a cost effective way; and to stimulate opinion in one another (Barbour 2007). Data generated through this process contributed to further refinement and saturation of some categories. The findings of this paper are based mainly on this stage. All discussions in interviews and focus groups were audiotape-recorded and transcribed verbatim. These concepts were developed by constant comparison until no new categories emerged (Strauss and Corbin 1989, Charmaz 2006).

Data analysis

The findings of the study suggested that the relationships between purposeful activity, sense of self and person-centred approach of those with dementia are intertwined. Carers, through engaging their relative in everyday activities, made an attempt to maintain a sense of self in their relative as far as possible, despite the relative's significant loss of cognitive and functional ability. Carers used a range of routine daily activities as a means of enabling their relative to achieve ends which ultimately enhanced their sense of self. The term relative is used for people with dementia who lived with, and were cared for by, their carers. Three key functions of using purposeful activities in everyday domestic settings were found to include:

1. To enhance their relative's autonomy and independence
2. To keep the person with dementia active
3. To act as a trigger which enables the person with dementia to improve their mood.

1) To enhance their relative's autonomy and independence

When carers became increasingly concerned that their relative made inappropriate decisions about critical everyday routine activities, including handling finances, dealing with electrical appliances and keeping hospital appointments, many carers developed their own strategies to maintain their relative's sense of autonomy and independence as far as they could. One approach was to provide a structure for their relative to continue doing various familiar tasks with their support (e.g. basic self-care including bathing, dressing and handling finances). This was especially the case when their relative would have forgotten to do something if they were left on their own. As Ellen said:

> *'My husband still does things for himself but I have to encourage him to get in the bath – I have my bath and then he jumps in after, because then he has got into a routine of doing it and I sort out all his clean clothes'. [Group 2]*

Some carers also made an effort to support their relative to continue contributing to the household chores, despite difficulties. This can be illustrated in the following quote by Sheila:

> *'My husband does little jobs, he takes the dog out. I have to coax him but that is his job – he washes up but – he gets sort of fed up with it really. He might do half and then leave it, and he washes up but it is all sticky ... mmm I get impatient?' [Group 1]*

It seems that by supporting their relative to engage in normal routine activities, carers tried to provide opportunity for their relative to continue doing what they would still do and preferred to do, even though it often taxed carers' patience. Nevertheless, many carers would consider it worth doing so because it enabled the relative to maintain confidence and exercise a sense of control. For example, Keith said:

> *'My wife really loves the garden – she is absorbed by it... What she likes doing is buying plants and I have to go along and buy all the plants but the bit that I don't like is that they lie there at the bottom of the garden – achieving very little; but she feels it is the thing that she always did; so I like her to be in the garden and she still feels, the way she does things, although they are different, because she still feels in control of the garden – give her both comfort and confidence'. [Group 4]*

This carer maintained his wife's confidence in gardening activity by supporting her in making a specific activity-related decision, and by creating a supportive environment for his wife to become absorbed in such an activity. Implicit in this was that he was able to promote the continuity in his wife's past interest, wishes and preferences through her engagement in a familiar pastime.

Carers often continued to support the autonomy and independence of their relative with cognitive decline although the decision to do so was often a balancing act, as illustrated in the quote below by Joy:

> *'The doctor asked my husband to stop driving. And he did say "yes" to the doctor ... although he would say to me, "Well I am still capable of driving perfectly alright". He did in fact change his mind and drive a bit after that when we were out in the country. I've to say, "Yes go for it", and then we would get to a main road and I would take over again'. [Group 5]*

As can be seen, after Joy's husband changed his mind about the initial decision to stop driving, she showed her willingness to maintain a trusting and respectful relationship with her husband. Joy realised that her husband missed his driving very much because he used to go on holidays with her in his car until he obtained the diagnosis. Hence, she was prepared to enable him, as far as practicable, to respect his wishes, and exercise his sense of autonomy. This in turn enhanced a meaningful interaction between her husband and herself through continuing to do something together in the partnership.

Taking risk, therefore, was often considered by carers as inevitable. Many carers often faced the dilemma of making a decision to encourage or disengage their relative from performing some everyday routine activities which appeared to be 'unsafe' acts or 'unwise decisions' for the relative, and sometimes for themselves. As these events occurred more frequently and became more unpredictable, carers had to become more alert and watchful of their relative's everyday performance and behaviour.

Hence, through maintaining the autonomy and independence of their relative's engagement in a familiar everyday routine, carers were able to promote continuity in their relative's personality traits, and in a sense of self which was still recognised by their carers, despite cognitive decline. Nevertheless, such an involvement often incurred a cost for carers in terms of their financial, emotional and physical inputs. They were frustrated by the lack of support from professionals in addressing such complex issues.

2) To keep the person with dementia active

Many carers attempted to explore various means to keep the relative's mind and body active. This is especially important when carers considered that their relative's concentration and reasoning ability had deteriorated further; and that they were not showing motivation to initiate and carry out any purposeful activities without assistance. Many carers made an effort to keep their relative stay 'active', as Nora said:

> *'I try to encourage my husband to dance and sing. I have a limited amount of success. He stands up and I put my arms around him, I know he is not very steady but he remembers what he has to do more or less and I do a lot of singing you know, to cheer myself up and I will say come on, you know this. I am always looking for ways to keep his mind – you know. I don't want him to slink, slump, slurp, I don't know the word – sink into a kind of chair'. [Group 1]*

By keeping their relative active, carers attempted to make a connection with old self of the relative and to encourage the relative to recall their past relationship.

An activity which many carers often mentioned was 'going-out' because it made their relative physically move about.

Some carers also used 'going out' (e.g. a trip to the shop, a ride in a car) as a medium to stimulate their relative to engage in a more meaningful conversation or social connection. Many found it beneficial to go out as a way to make a change to the atmosphere at home, as showed by Tim below:

> *'When you actually go out with her (wife) she is different. I think that she tries to make an effort when you are out, more so than in the house. When we are back in the house and it is just two of us she seems to go down a couple of rungs of the ladder'. [Group 2]*

However, 'going out' became an impossible activity for many carers when they could not always give their relative close supervision, as shown by Mary below:

> *'I always found that it was quite frightening if I had gone anywhere, because my husband and I always used to go to see shows (in theatres) and, you know, I would say do you want to go to the toilet before we go in, and he would say yes, and he would disappear... And then a couple of times I found him just sitting on the steps that were coming down into – and he didn't know where he was'. [Group 5]*

Some carers also considered the need to keep their relative's mind busy by using some kind of mental stimulation through entertainment, especially when they realised that their relative spent more time at home. Many tried to look for a way to promote laughter and happiness in their relative. It appears that passive activities such as watching television and video tapes, listening to music were beneficial in terms of mental stimulation for the relative.

Many carers felt that they there was societal pressure on them to keep their relative occupied shown in a quote below by Julie:

> *'After my husband was diagnosed Dr M said, try and keep his mind busy – antidepressants didn't work. And so probably in the first few months of him being diagnosed I tried things like scrabble, snap, and the music that he liked, but he couldn't do any of them, ... so I kept him walking every single day... But by making him fit, some nights he wouldn't sleep at all ... he would get up and wander and ... and I was frightened of him falling down the stairs.' [Group 2]*

The forgoing example illustrates that carers are often advised to keep the person active, because doing so it is seen as common sense knowledge. Nevertheless, carers often had to develop their own strategies to do so, without support.

In reality, carers also needed to regularly monitor their relative's changing performance and to adjust the environment and the task accordingly. Some carers felt that a supervisory responsibility was imposed on them to protect their relative from harm. Some talked about their frustration at not always knowing if they had made the right decisions to adapt a familiar activity for their relative. An example of this can be illustrated in the following quote by Nora:

> *'My husband started to wet the bed, so I can't get him out of bed so I bought a bed that lifts up the head and the feet but he fights me. He is beginning to grab my wrists. I wouldn't say he is violent – you have to be, patience is a thing I try to maintain. I don't know if there is anything else I can do'. [Group 1]*

This carer had worked on her own initiative and brought a piece of expensive equipment to help with her husband to get on and off a bed. However, she was upset and frustrated by the aggressive reactions of her husband when using the equipment in helping him with his mobility difficulty. This demonstrated that a piece of potentially beneficial assistive technology could trigger aggressive behaviour in the person with dementia if it was not introduced with necessary training in a sensitive manner. As can be seen in this case, aggression could be provoked by the lack of knowledge and skills in working with people with dementia.

In short, many carers attempted to keep their relative active. However, they often lived with a lot of uncertainty.

3) To act as a trigger which enables the person with dementia to improve their mood

Many carers talked about using an activity as a trigger which then enables the person with dementia to change their mood and become more cooperative when offering assistance for other caring tasks. An example of this is illustrated by Sandra below:

> *'My husband didn't want to get out of bed and then gradually, he was never away from home... So I have to motivate him to do something... He always loved music, but there was one – It is the Ink Spots. If I wanted him out of bed, wanted him to do anything, to go for a walk, the Ink Spots... when he heard the Ink Spots it was amazing and suddenly his face was calmer, I mean, ...something clicked and then he would get up and then I could dress him and we would have breakfast, and then he was happy. And if you had him in that mood, that happy, then you can suggest, we went for a walk – that music – it was just the motivator'. [Group 2]*

Certain kinds of activities have been identified by carers as a trigger to elicit a change of mood in the person with dementias, from being aggressive to being calm. This enabled carers to work cooperatively with their relative in taking part in everyday essential and purposeful daily activities such as dressing, toileting and bathing.

Many carers worked hard to develop strategies for engaging their relative in activities which prevented them from feeling restless by offering an opportunity to take part in meaningful activity, so that the carers could continue utilising the remaining ability of the relative. This is illustrated by Janet:

> *'My husband – kind of following me around a lot. So I have tried things like helping with the vegetables and things like that. Because he was always quite a good cook, he used to like cooking and some days he could do it and other days he couldn't... and some days it will be chopped in minute little slices, and other days it will be in big chunks, but I think well it doesn't really matter'. [Group 5]*

Implicit in this is that carers had to negotiate with their relative and agree a manageable goal for a task which was also meaningful to both their relative and themselves. For example, Janet found the symbolic meaning of the relative's action as a way to maintain a connection with the old self and a meaningful relationship. Carers also needed to adjust their own standards and value of the task performance; as well as to provide an appropriate level of guidance and supervision. Some carers became even more innovative in their approach. Nevertheless, through trying to engage their relative in meaningful activities, carers' own sense of self confidence was often challenged.

Despite this, for many carers, findings ways to communicating with and keeping the 'old self' was a major motivating factor in continuing to look after the relative at home,

Lessons learned from the study

Support for family carers is especially important because current UK government policy stresses the need to enable people with long-term conditions to live well at home for longer and so delay entry into institutional care (e.g. the National Dementia Strategy, DH 2009; the Carer Strategy, DH 2008, Prime Minister's challenge on dementia, DH 2012). The significant role of family carers in supporting the continuing activity needs of their relative in the community cannot be under-estimated.

This study brings a deeper insight into the process in which the activity needs of people with dementia are being met by home carers. Such insight is essential for practitioners in identifying and developing a more realistic intervention strategy which will work in effective partnership with family carers so as to meet the needs of people with dementia, using a person-centred approach. Such a partnership ultimately enables the carers to develop a more effective therapy process.

Individuals with dementia find it difficult to maintain a sense of self and identity over time without support (Gilles and Johnson 2004, Naylor and Clare 2008). Kitwood and his colleagues argued that a sense of self of those with dementia could be maintained and enhanced by those who provide care for them (Kitwood and Bredin 1992). The family carers in this study provided empirical evidence of this process. Through engaging their relative in meaningful daily activities, carers initiated a range of activities which enabled their relative to enhance a sense of self. These activities aimed at: i) enhancing their relative's autonomy and independence; ii) keeping their relative active; iii) acting as a trigger to elicit a positive mood. The findings also supported Kitwood's view of person-centred care for people with dementia that care practice takes place in the context of relationships (Kitwood and Bredin 1992, Kitwood 1997).

Kitwood's work on person-centred care has been criticised for lacking sufficient evidence, and as based largely on experience from institutional care (Adams and Gardiner 2005, Nolan et al 2002). In contrast, the data of this study are drawn from family carers' own accounts of their experience in engaging a relative with dementia in daily activities at home. The findings support many of Kitwood's ideas (e.g. positive interaction, inclusion, sense of control and activity needs), and have provided empirical evidence to illuminate how a sense of control in those with dementia could be maintained by family carers in a person-centred manner. This involved valuing the relative as a unique individual with a past history; consulting them about their preferences; appreciating their subjective experience and providing comfort and support when distressed. Hence, this research broadens understanding of the processes involved in how carers contribute to home-based activity intervention within a non-institutional setting. It also provides an insight into the understanding of how family carers used everyday occupation to promote the continuing activity needs of their relative.

It was evident that carers' daily interactions with their relative were complex and evolving processes, involving the use of a range of skills and knowledge, including communication skills; their understanding of dementia; of goal-setting for meaningful activities at different stages of dementia; and of mobilizing necessary resources. Without formal training, carers in this study showed that they had the interests of their relative at heart, and tried to maintain a sense of self in them. The data provided insights into the complexity of carers' interactions with the relative, day in day out; and how carers continually developed modified strategies for their everyday interactions with their relative over time. This promoted a sense of autonomy in their relative as far as was practical. The findings were consistent with literature which suggested that carers were often highly resilient and resourceful (as found by Searson et al 2008, Watkins et al 2011).

The findings also highlighted how the experiences of family carers could be an invaluable resource for professionals who wish to work collaboratively with carers. They recognised the long-term commitment of family carers in their role. Such appreciation of the carer's role is crucial to the implementation of the government Carers' Strategy which aims at ensuring carers are 'respected as expert partner' by 2018. The Strategy envisages that carers would have the ability to access the integrated and personalised services they need so that they would enable their relative to be 'a full and equal citizen' (DH 2008, p. 7).

An aspect emphasised in this research was that providing mechanisms of support as a family member was very different from doing so for paid carers (the target audience for Kitwood's original mechanisms of support). The findings suggested that, as dementia of their relative progressed, family carers experienced increasing difficulty in adopting certain aspects of the positive person-work approach, 24 hours a day and 7 days a week over an indefinite period of time. This was especially so as they had had no training in dementia care and received limited support from health and social care professionals. In some circumstances, the notion of positive interactions and person-centred approach might place a heavy responsibility on a family carer, and make them feel guilty when they had to relinquish caring responsibilities. For example: if the relative, who used to be very affectionate, suddenly became threatening either verbally or physically, carers found it difficult to maintain a positive attitude. Aggressive behaviour sometimes became the 'final straw' for a carer, and to a decision that residential care for a relative was necessary. This finding is consistent with other studies which examined factors influencing carers' decisions on institutional care for their relative with dementia (e.g. Gallagher et al 2011). Hence, there is an implication for providing carers with training on not only in general person-centred work, but also in specific techniques and approaches when more general principles were not working. This reinforces the need to support carer's training so that they could offer an enabling care environment, one which promoted a sense of control, social confidence and hope in those with dementia (Kitwood 1997, Sabat 2008). Moreover, the findings also support carers' need for regular break from their caring role as highlighted in recent government policies (DH 2010, 2012).

Implications for occupational therapy

The current ethos of person-centred community-based care for dementia and their carers is consistent with the core values of occupational therapy which emphasise the individual's independence, autonomy, dignity and social inclusion by enabling engagement of the people in meaningful occupations (College of Occupational Therapy 2007, 2012). Moreover, the role of occupational therapy supporting individuals including people with dementia and their carers in the community has been recognised in government policies and National Institution for Centre of Excellence guidelines (e.g. DH 2001, NICE 2006, 2008).

The findings of this study showed that trying to meet the continuing activity needs of a relative with dementia on a daily basis can be a demanding task for family carers. Activity engagement took up a great deal of carers' daily time and effort during the caregiving journey. All the carers attempted to 'engage and enable' their relative in everyday activities which had specific meaning to the person, both in their past and present life situation. This was in addition to other more routine caring responsibilities. The activities with which carers were involved were largely related to general areas of concerns for an occupational therapy input including self-care, household management and leisure. The list of activities was unlimited and full of sometimes mundane activities including for example: enabling their relative to have a regular bath, going out for a walk by themselves or with carers, watching television together, listening to music and navigating for their relative when driving. In order to ensure that each of these activities was meaningful and relevant to the value and interests of the individual, carers constantly had to make decisions.

Activity engagement is a complex daily decision-making task for carers. Carers often did not feel that they had the necessary skills and confidence in daily management in dementia care. This finding was consistent with other studies (e.g. Vikstrom et al 2005, Keller et al 2007). These showed that if person-centre care in dementia care is to be adopted fully in a home setting, it is crucial to support family carers in meeting the continuing activity and psychosocial needs of those with dementia. This may include, for example, how to deal with difficult circumstances when they noted signs of frustration, agitation and insecurity shown by their relative during a task performance; and how to develop preventative strategies before crisis situation occurred. This is especially so because more than 90 per cent of people with dementia experience behavioural and psychological symptoms such as aggression, agitation, delusions and hallucinations (Fernández et al 2010). Hence, there is a need for occupational therapy practitioners to support carers in selecting from a range of strategies which carers had initiated, and so lead to more effective intervention. It is also important to assist carers to recognise those strategies which might lead to failure or frustration. If support for carers is not provided, it is be possible that carers eventually could neglect needs of those with dementia.

The findings of this study showed that many carers attempted to keep their relative physically and mentally active. However, they often lived with a lot of uncertainty, and guilt resulting from making decisions on how to stimulate their relative to take part in activities. Some participants were concerned that activity engagement might have accelerated the deterioration of their relative by over-stimulating the brain. When carers were asked to talk about their experiences, both positive and negative, they tended to focus on offering examples of negative signs (e.g. apathy, low mood, unresponsiveness and anger). This tendency may reflect a possibility that carers considered the effect of positive experiences of their engagement with the relative to be short lived. This may have been partly due to the fact that many carers had been told by the doctors that dementia was an 'incurable disease' and that there was 'not a lot that could be done' by medical professionals or health and social services staff. This research supports the government Dementia Strategy (DH 2008, 2012) which points to a need to shift the culture in which we treat people with dementia to a more positive attitude (i.e. dementia-friendly communities across the country), which in turn would lead to belief that the people with dementia can be supported to live a better quality of life, despite progressive cognitive decline. Occupational therapy is well placed to support the implementation of the policy.

The findings showed that, despite difficulty, a source of carer satisfaction could be drawn from: i) their ability to engage the relative in a range of appropriate daily activities in order to achieve certain goals (e.g. maintaining dignity, helping the relative cope with difficulties, getting pleasure from seeing their relative enjoying themselves and keeping active); ii) the extent to which their relative and others appreciated their effort. These findings are consistent with the work of Lundh and Nolan (2003). The findings have implication for occupational therapy to develop outcome measures for not only person-centred home-based activity programme but also carer's intervention.

The study had focused on co-resident carers' experience in their engagement of people with dementia, at home. One of the strengths of this research is the fact that data was based on family carers' own stories through in-depth interviews and focus groups. These were very experienced carers who had been through the process of engaging their relative in everyday routine activity. They were therefore in a position to talk about what might be the most appropriate strategies for activity engagement in a non-institutional setting.

Conclusions

This study sheds light into some of the ambiguous and complex circumstances which carers confront in their everyday decision-making when engaging their relative in activities. It provides a fuller understanding of carers' perceptions of how the taken-for-granted everyday activity can be used to promote a sense of self in their relative. Moreover, the data support the centrality of the carer-relative relationship in dementia care within the context of a person-centred approach. Such an approach cannot be implemented successfully without providing effective support for carers in their role. This study reinforced the need to increase professionals' recognition of what carers can do for their relative and for occupational therapists to support them in that effort.

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Intervención de Terapia Ocupacional con familiares de usuarios de servicios psiquiátricos

Occupational therapy intervention with families of users of psychiatric services

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Resumen: *Esta experiencia se inicia en 1999 en el Hospital Psiquiátrico "Dr. José T. Borda" de la ciudad de Buenos Aires, al detectar las necesidades de las familias de pacientes externados que padecen trastorno mental severo (TMS) y son usuarios del servicio psiquiátrico ambulatorio. Se crea un espacio donde se informa y se trabaja con los familiares, situaciones comunicacionales y convivenciales de la vida diaria en pos de mejorar la calidad de vida familiar.*

El uso de esta metodología de consenso entre el equipo interdisciplinario integrado por psicólogo, psiquiatra, terapeuta ocupacional y la familia de los usuarios en un entorno participativo, permite priorizar y diseñar estrategias de cambio adecuadas al contexto en el que se va a aplicar, mejorando los procesos de información entre los actores sociales, por lo cual se transforma en una estrategia para implementar no solo con TMS, sino con otros trastornos, deficiencias, desventajas y situaciones de vulnerabilidad.

La perspectiva es centrada en las personas, el paciente y su familia, en un taller grupal con familiares; las intervenciones son en congruencia con lo que los familiares necesitan: ser escuchados, estimulados a reflexionar, a solucionar problemas cotidianos que mejoren la convivencia diaria y la recuperación del paciente.

Palabras clave: Esquizofrenia, calidad de vida, convivencia, red de apoyo.

Abstract: *This experience begins in 1999 at "Dr José T. Borda" Psychiatric Hospital in Buenos Aires, upon detecting the needs of families of out-patients with severe and persistent mental disorders, who are users of psychiatric ambulatory services. A space is created where families are informed and professionals work to improve family communication, coexistence in daily life, and quality of life.*

The use of this consensus methodology by the interdisciplinary team, including psychologist, psychiatrist, occupational therapist and the families of the users in a participative environment, facilitates setting priorities and designing strategies for change adapted to the context, improving the processes of information among the social actors. It becomes a strategy to be implemented not implemented with persons not only with severe and persistent mental illness, but also with other dysfunctions, deficiencies, disadvantages and vulnerability situations.

The perpective is centered on people, the service user and his/her family, in a workshop with family members. The interventions are consistent with what the families need: to be heard, stimulated to reason, to solve daily problems that improve daily coexistence and the patient's chances of recovery.

Key words: Schizophrenia, quality of life, coexistence, support network.

Introducción

Uno de los derechos humanos primordiales y esenciales es el derecho a la salud y para el ejercicio del mismo se deben tener posibilidades de acceso igualitario a los servicios, a los programas y a las prestaciones que estos han organizado para la atención y tratamiento. Asistir en una terapéutica ocupacional grupal a familiares abreva en los elementales principios de promoción y adecuada asistencia.

Acordamos que una de las señales más conocidas de los trastornos sociales es la situación familiar y que a sus integrantes cada vez se les hace más complejo hacer frente a las funciones que la vida cotidiana impone.

Actualmente se ha ensanchado la ruptura de la red de apoyo social y familiar, este tejido básico tan sensible y a la vez tan esencial en la promoción de la salud; es fundamental entonces encarar la transformación de los sistemas de atención en concordancia con los paradigmas actuales, que generaron que las familias acrecienten su función como recurso de cuidado y de sostén. No obstante ser un recurso principal y necesario de soporte social para el paciente y/o usuario, la problemática de la familia y sus necesidades son escasamente atendidas; éstas precisan ser observadas y escuchadas, requiriendo de información y asistencia.

Debemos recoger información de sus necesidades y examinarlas, ver las redes de apoyo existentes a nivel local, dado que la familia es determinante de la cultura que habita y generar construcciones de ambientes inclusivos con respuestas sociales e iniciativas colectivas.

Para que los terapeutas ocupacionales respondamos a las necesidades sociopolíticas de las comunidades y de las poblaciones promoviendo la salud, es indispensable construir entornos de apoyo a las familias. Necesitamos organizar espacios donde se promuevan, a través de la reflexión e información, soluciones a problemas concretos que redunden en el bienestar de los usuarios de servicios y en el mejoramiento de la calidad de vida del grupo conviviente. Las intervenciones en la familia dentro de este ámbito ocupan un papel central para aliviar el sufrimiento y aminorar las repercusiones de eventos estresantes que desestructuran su dinámica.

Esta posición se ve representada en la participación y colaboración de las familias acordes a las necesidades del usuario; conocimiento y aceptación de la existencia de la enfermedad o de la situación desventajosa que padece, adquisición de conciencia de la situación en que se hallan y en la cual quedan involucrados todos los integrantes de la familia y/o el grupo conviviente.

Los integrantes del grupo conviviente necesitan cuidados, pues se enfrentan diariamente a un número elevado de situaciones complejas que conllevan implicancias tanto a nivel físico como emocional. Estas situaciones repercuten de manera significativa, no sólo en la vida de la persona padeciente y en su ámbito familiar inmediato, sino en el social más amplio y supone un fuerte impacto sobre el proyecto vital de las personas. Desde una concepción integral de la salud ocupan un lugar fundamental y es desde esta perspectiva que nos preocupan todas las disfunciones y malestares que sufren en la cotidianeidad y los aspectos convivenciales en relación al que padece de una enfermedad o se halla en una situación desventajosa.

Los terapeutas ocupacionales utilizamos como recurso estratégico la psicoeducación; este conjunto de técnicas de comunicación son utilizadas para informar y transmitir la enseñanza a familiares acerca del padecimiento y las formas de aliviarlo. Como integrante del equipo interdisciplinario provee los conocimientos sobre el trastorno del padeciente y las distintas conductas del mismo y por otro lado vehiculiza de manera efectiva la autonomía en el desempeño de las actividades de la vida cotidiana en sus roles y en sus dimensiones, individual, grupal, comunitaria y la comprensión de las mismas. Esto implica muchas y variadas actividades de diversa dificultad; hay que identificarlas dentro del contexto en el que cada familia se desarrolla y que integra uno comunitario social más vasto. El terapeuta ocupacional debe llegar a conocerlas y realizar intervenciones singulares donde se promuevan las actividades de la vida diaria que cada familia organiza para sí y le da valor y significado; el terapeuta ocupacional las posibilitará y hará hincapié en el proceso.

Antecedentes

La organización y los resultados de la realización del *Taller con familiares de pacientes que padecen de esquizofrenia* que se lleva a cabo desde el año 1999 en la consulta externa del Hospital Borda de la ciudad de Buenos Aires, coordinado por la Licenciada Silvia Blanco, psicólogo clínico y por la terapeuta ocupacional Elisabeth Gómez Mengelberg, sirve como antecedente y es posible de ser replicada con otras patologías o situaciones desventajosas. Los otros miembros del equipo interdisciplinario participan en el taller cuando se realizan charlas estructuradas acerca de temáticas específicas.

Desarrollo

Se genera este taller para canalizar una demanda importante y apremiante por parte de los familiares de los usuarios del servicio; se crea entonces un espacio de reflexión sobre la problemática de convivir con una persona que padece de un trastorno mental severo como la esquizofrenia y se ofrecen herramientas para resolver situaciones y problemas, interviniendo con estas familias.

La guía de estos encuentros grupales es la información sobre la enfermedad, su pronóstico, tratamiento, visualización e interpretación de conductas. El objetivo es influir en la evolución de cada uno de los usuarios trabajando con las familias sobre las actividades de la vida diaria, detectar sus expectativas en relación con la recuperación del usuario y adecuar éstas a la realidad actual.

Se brinda apoyo emocional, se promueve la reflexión y la jerarquización de los problemas; el brindar información disminuye el nivel de angustia y la exigencia hacia la persona que padece por parte del grupo conviviente, mejorando considerablemente su calidad de vida y por extensión la eficacia del trabajo en la recuperación del usuario.

El taller está dirigido a familiares y/o grupo conviviente. La no asistencia del usuario obedece al objetivo que sus miembros puedan expresar libremente sentimientos y emociones que los vinculan al usuario sin la presencia de éste. Se planificó la frecuencia de estos encuentros quincenalmente para evitar que tengan que ausentarse o pedir autorización en el lugar de trabajo con asiduidad y son matutinas debido a la organización hospitalaria. A los usuarios se les ofrece psicoterapia grupal o individual en otro horario y con otros profesionales.

Las familias son orientadas y alentadas a concurrir por el equipo interdisciplinario que asiste al usuario; este es un ofrecimiento de tratamiento que no está signado por la obligatoriedad, siendo ésta una decisión de funcionamiento tomada por el equipo profesional para evaluar la disposición familiar. La duración en el tiempo de asistencia se relaciona con el momento de la enfermedad que el usuario esté atravesando y el grado de comprensión y utilización de estrategias por parte de los miembros de la familia.

Hay familias que con altibajos llevan casi dos años asistiendo, convirtiéndose en grandes aliados y colaboradores; las que recién ingresan se ven reflejadas en ellas y son incentivadas a identificarse con sentimientos de ayuda mutua, solidaridad y cooperación.

Cada grupo familiar se contabiliza como uno aunque sean varios los integrantes que asisten; a veces vienen los padres y hermanos, otros sólo la madre, o las novias. El número promedio de grupos familiares que asisten a cada sesión es entre cinco y ocho.

Desde el inicio del tratamiento de una persona que padece de esquizofrenia, los familiares esperan que los resultados aparezcan rápidamente. En la esquizofrenia, para que los tratamientos presenten resultados, debe darse dentro de un proceso en un período de semanas y meses, donde es preciso mantener la esperanza realista y ejercitar la paciencia. Entretanto las primeras mejorías pueden ser percibidas en términos de días.

Cuando decimos tratamiento nos referimos a un abordaje interdisciplinario psicoterapéutico, ocupacional, psiquiátrico/psicofarmacológico y social.

En el taller se estimula a todos los que asisten a hablar abiertamente de los problemas de la convivencia familiar acerca de lo cotidiano y se evidencian importantes necesidades de variada información, ya que identificamos un serio desconocimiento acerca de cómo proporcionar condiciones de posibilidad para que el usuario de servicios que padece de esquizofrenia pueda tener una vida lo mas autónoma posible y que eso redunde en la reducción de malestares familiares.

Destacamos que existe una concientización que resulta compleja, hay una distancia entre entender determinada situación y saber convivir con ella; convivir con una persona que padece de esquizofrenia es colocarse en una serie de situaciones complejas interrelacionales y el camino para tratar con ellas es un aprendizaje constante.

Algunas de las situaciones concretas y puntuales que se trabajan en el taller son: “no se quiere bañar”, “no colabora con las actividades del hogar”, “duerme todo el día”, “no sabe hacer las compras”, “no se despierta solo”, “mira televisión todo el día”, “si se le dice algo se enoja”, “habla poco, a veces no contesta”, “no quiere ir a los festejos familiares”, “no sabe viajar solo”, “si dejo que caliente la comida la quema” y otras que afectan tanto al ritmo cotidiano familiar.

Cuando la persona que padece de esquizofrenia y su familia entiende que los tratamientos psiquiátrico-psicofarmacológicos, psicoterapéuticos, terapéuticos ocupacionales y sociales le posibilitan una vida mejor y menores sufrimientos, se abre el espacio para que el tratamiento adquiera el sentido de reconstrucción de proyectos para el futuro. Es menester de los profesionales de la salud facilitar ese entendimiento a la familia y al usuario.

Las relaciones familiares no son siempre armoniosas; muchos tienen una mala convivencia con serias dificultades relacionales y otros problemas anteriores e independientes de la esquizofrenia del que la padece. Es muy frecuente que las personas que tienen este trastorno muestren un comportamiento que dificulta el acercamiento de los familiares y genera conflictos. En este taller, un objetivo primordial es el reconocimiento y realización del potencial familiar; este espacio productivo permitirá la incorporación de nuevos aprendizajes para pensar en estrategias en pos de comprender y posibilitar la modificación de aquello identificado como problema. Lograr la búsqueda, el desarrollo y la instrumentalización de diferentes alternativas adecuadas para resolver las dificultades que surgen en la cotidianeidad con el familiar que padece, disminuyendo las ansiedades y preocupaciones del entorno.

Es esencial para nosotros los terapeutas ocupacionales llegar a conocer el modo en que las personas experimentan su vida cotidiana y qué representaciones hacen de su propia condición, para realizar las intervenciones pertinentes.

Es una herramienta eficaz agrupar a las familias en espacios donde se trabaje propositivamente el lugar social de los trastornos mentales severos, los prejuicios y tabúes que hay respecto a este tema, el concepto de normalidad, de supuesta salud, los sentimientos de culpa de los familiares, la construcción de los roles y cómo influye esto en la asunción de este TMS, la elaboración de los procesos de duelo. El contacto autogestivo entre los miembros posibilita enfrentar más favorablemente situaciones de crisis y disminuir el estrés.

Se estimula a los intervinientes a tener una disposición de apertura para tratar los problemas, ya que sabemos que la esquizofrenia no es la única causa de las dificultades en la convivencia; hay posiciones de distintos miembros de la familia que pueden generar conflictos, por lo tanto fomentamos el apoyo solidario y cooperativo entre las familias.

Acorde a la perspectiva del modelo orientado hacia la recuperación, fomentamos la creación de grupos de autoayuda informales y a su vez impulsamos la concurrencia y el acercamiento a asociaciones de familiares nacionales e internacionales que cuenten con una organización formal, para que hagan valer sus derechos como familiares de usuarios y defiendan los de su familiar padeciente.

Contribuimos para que la persona que padece de esquizofrenia se sienta integrada al ambiente familiar y que se la incentive en su autonomía y en la realización de actividades de la vida diaria, donde pueda mostrar su potencial y sentirse capaz de enfrentar nuevas situaciones.

Explicitamos que algunas actividades pueden necesitar de un acompañamiento por un determinado tiempo y gradualmente ser delegadas, reconociendo la capacidad de la persona.

Muchas familias no superan la etapa de “enojo” y/o negación de la enfermedad y en consecuencia la persona que padece de esquizofrenia está mucho tiempo sin los tratamientos adecuados y esto contribuye a deteriorar las relaciones familiares y determina una peor evolución de la dolencia.

La recuperación del usuario a la cual nosotros contribuimos al trabajar con la familia en este taller, no significa superar la esquizofrenia y conseguir que sus efectos y síntomas desaparezcan completamente, ya que es muy infrecuente que ello suceda y no se debe alimentar esta esperanza.

La recuperación se fomenta encontrando soluciones prácticas y cotidianas para mejorar aquello que es posible y procurando la manera de tener una vida con una buena calidad, siendo ésta una esperanza realista y posible. Por ello, la utilidad de este tipo de intervenciones podría ser considerada como parte de la estrategia global de tratamiento de la enfermedad esquizofrénica.

Consideraciones finales

Brindar la oportunidad de participar en un actividad grupal con otros familiares, compartiendo inquietudes y experiencias, es favorecedora de búsquedas de alternativas colectivas de salud y de mejoramiento de la calidad de vida y favorece la construcción de una red familiar y social de apoyo y de seguimiento para las familias que tienen una persona o una situación de desventaja, deficiencia o discapacidad.

La concurrencia sostenida en el tiempo por parte de las familias al *Taller con familiares de personas que padecen de esquizofrenia* y los efectos cualitativos sobre dimensiones clínicas de los usuarios, relatados y evidenciados por las familias, trae como consecuencia un mejor funcionamiento en la convivencia cotidiana y nos habla de la eficacia del dispositivo.

Agruparlos con una problemática en común facilitó el surgimiento de sentimientos de cooperación y de solidaridad entre pares. Se evidencia una mayor disposición para entender las intervenciones de los profesionales, así como un mayor cumplimiento de las indicaciones generales sobre el tratamiento.

El trabajar con las necesidades de cada integrante de la familia y que cada uno cuide y preserve sus actividades y ocupaciones personales ayuda a evitar la sobreprotección, la sobreinvolucración, la sobrecarga y el desgaste, permitiendo el desarrollo y la autonomía del usuario.

Reconocemos la prioridad que en el mundo de los adultos se da a las responsabilidades de trabajo y familiares, por lo tanto la construcción de espacios grupales de taller con las familias y/o personas convivientes agrupadas tras una actividad y objetivo común ayudan a hacer mejor uso del tiempo que tienen y un mayor aprovechamiento de las indicaciones, con el consiguiente beneficio de la armonía en la convivencia.

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Family empowerment at Centro Ann Sullivan del Peru


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Abstract: *Centro Ann Sullivan del Peru (CASP) is a non-profit educational institution in Lima serving children and adults with different abilities, their families, and professionals from Peru and all over the world. CASP was founded in a family empowerment model in which families participate as members of the team and receive continuing education to promote engagement, function, and independence in the lives of their children. The authors (two occupational therapists from the United States) traveled to CASP to immerse in this culture of family empowerment, support, and mutual respect. The authors conducted family training sessions as well as individual consultations and explored ways to translate the CASP model into practice in the United States.*

Key words: Family empowerment, CASP model, inclusion.

Introduction: CASP history

Centro Ann Sullivan del Peru (CASP) is a nonprofit educational organization founded in 1979 by Dr Liliana Mayo to meet the needs of people with different abilities and their families. The center, named after the well known teacher of Helen Keller, is currently providing services to over 450 people with different abilities and their families (Schroeder 2006). CASP's comprehensive programming provides services for individuals with different abilities from birth to adulthood, ranging from early intervention and intensive schooling to school inclusion and supported employment, which currently hosts 100 people with different abilities in more than 30 workplaces in Lima and other provinces.

Functional natural curriculum

Grounded in a ten-point philosophy (Table 1) and a behaviorist approach, CASP's Functional-Natural Curriculum facilitates the growth of behaviors required to maximize independence in work and daily living. By capitalizing on individual strengths and preferences, CASP is able to identify areas of occupation that are motivating and meaningful to individuals and subsequently teach the requisite skills to optimize success and independence. This was seen in action in CASP's newest program, La Lavanderia, to prepare students for future employment. Through networking and donations, CASP received two washing machines and dryers which they arranged to model a laundromat. Students in intensive schooling, who had a higher level of need than other CASP students, found great motivation and meaning in working in La Lavanderia. Students, specialists, OTs, and family members collaborated to find ways for each student to contribute and develop skills for future work opportunities. The authors supported CASP efforts in La Lavanderia by performing an environmental audit and making visual supports, adaptive equipment, and assistive devices to promote student independence and success.

Table 1. CASP philosophy

1. People with different abilities can learn if taught with the correct individualized procedures.
2. All people want to be independent, productive and happy, and should be provided the education and opportunities to achieve their goals.
3. All people should be included at home, school, community and the work place.
4. All people should be treated as we ourselves want to be treated … with kindness and respect.
5. Families can be the most effective teachers of their children if they are taught the proper skills.
6. Professionals should work as partners with families in the education of their children, each one learning from the other.
7. Teachers should first be friends of their students.
8. Focus on what students can do and not on what they cannot do.
9. Student's environments should be filled with supportive people who believe in their success.
10. Teaching and learning is a process that should be continued throughout life.

The CASP model abroad

The success of CASP's approach has drawn individuals from across Peru and the world to the center. Over the years, CASP has grown to become a world-renowned model for education, inclusion, training and research. The CASP model has been exported to 8 schools across Latin America including

Argentina, Bolivia, Brazil, Ecuador, Guatemala, Spain, and Panama. Furthermore, CASP has formed a number of partnerships, hosting students, researchers, practitioners, and volunteers from countries around the world (CASP n.d., Mandic and Heymann 2009). By way of their Distance Learning Program, over 10,000 families and professionals from a total of 63 Peruvian cities and 9 additional countries have been trained. An additional 160 professionals from 19 countries and 206 professional from 21 Peruvian provinces have been trained via the International Internship Program (CASP n.d.).

Family empowerment model

One of the driving forces behind CASP's success is its use of a family empowerment model and training programs as noted by visiting occupational therapy consultants. Staff strongly believe that inclusion – in school, in the community, in life – begins in the home. CASP staff assert that parents are responsible for 70% of the effort required to help their children succeed (CASP n.d.). In order for students to be successful, families and staff must partner together for the student's education and learn from one another. At CASP, families are involved in educational decisions and are active participants in their child's classroom. Parents must be considered equal members of the educational team along with professionals, since both have much to contribute. CASP staff have found that teachers become better teachers when they learn from parents, and parents become better parents when they learn from teachers. An attitude of mutual respect is essential for successful teamwork (Mayo and LeBlanc 2010).

Family training

CASP's philosophy declares that families can be the most effective teachers of their children when they are taught the proper skills. To promote effective teaching strategies and maximize carryover of learning between school and home, all families participate in an extensive training program. The program emphasizes finding ways to motivate students to learn and maintaining high expectations for students' achievement (CASP n.d.).

Training workshops

Upon enrolling their student in CASP, families undergo a series of training workshops that empower them with the skills they need to be the best teacher of their child (CASP n.d.). An introductory course explores families' attitudes about disability and expectations for their child. CASP staff reinforce their core value of treating all people with kindness and respect, as well as focusing on the student's abilities. The CASP philosophy emphasizes that a positive, strengths-based attitude, along with a supportive environment, can help the student succeed. During these sessions, CASP staff highlight the importance of parent participation in promoting student success. Sessions are interactive and dynamic, allowing participants to network with staff and other parents, to ask questions, and to reflect on their own strengths and limitations.

In-home trainings

Social workers and teachers, called Specialists, conduct home visits and in-home trainings throughout the year. These visits occur several times per year and help strengthen the relationship between families and staff. The purpose of these visits is twofold: First, visiting families in their homes allows staff the opportunity to help families apply CASP's teaching strategies in their own homes, with guidance and feedback as needed. For example, a student who is working on independent mobility at school may face unique mobility challenges at home. Working together, staff and families can help coach the student and enable him or her to be more independent. Second, staff are able to observe the student in his or her home environment and further their understanding of each family's day to day reality; some families live in the street, some don't have light, water, and bathrooms, while others may live in relative affluence (Mayo and LeBlanc 2010). This allows staff to gain a more complete understanding of who the student is as a person. Seeing a student in his or her home can provide valuable information on the student's interests, strengths, and abilities outside of school. Home visits also give insight into obstacles hindering a student's participation at home, school, or in the community. Barriers the authors noted while visiting student homes included a lack of accessible transportation, having to traverse steep and uneven terrain to access students' homes, and lack of appropriate or affordable medical care nearby.

Classroom trainings

Families are also trained in CASP classrooms to broaden their understanding of CASP's teaching techniques and to further assess the student's progress toward educational goals. To reinforce CASP's philosophy of using individualized teaching methods, parents and specialists work together to adapt daily lessons to optimize the child's learning.

Families team up with professionals to provide consistency and carry over between home and school. In order to capitalize on the knowledge and unique perspectives families hold, CASP specialists often ask family members about the students' strengths, interests, and home routine. In return, family members may ask specialists for guidance in helping the student successfully participate in valued activities, such as sitting down for a meal with other family members. Both share insight on strategies they have found beneficial to help the student succeed both at home and in the classroom.

This collaboration provides consistency as well as opportunities for the student's skills to be transferred to between home and school settings (Mayo et al 2008).

A beautiful example of this partnership was seen in one particular CASP classroom. A student, an 18-year-old boy with severe cerebral palsy, was in the process of learning to feed himself using a spoon with the assistance of his mother. Based on what she knew about the student's food preferences and feeding abilities, his mother brought in snacks for him to try during each feeding session. She also experimented with different utensil designs – adding a rubber band around the student's closed fist to aid in grasp, for example – to allow her son to hold the spoon with greater ease. The boy's mother noted his movement patterns and reactions after each bite, and shared her observations with the specialist. The CASP specialist, in turn, made recommendations for timing each bite and varying the type of food presented, to avoid the student losing interest. Together, the boy's mother and specialist were able to create a snack time routine and set up to enable him to feed himself more independently, both at home and at school.

School of families

CASP staff acknowledge that the extent to which families can teach what they intend depends on whether they know how to teach effectively. In order to enable families to be more effective teachers, CASP provides family education throughout the duration of a student's time at the center (Mayo and LeBlanc 2010). In addition to the above-mentioned training sessions, CASP families receive over 170 hours of annual training through the School of Families. Each family has their own annual individual educational plan (IEP) for learning the skills they need to learn to be effective parents and teachers (Mayo and LeBlanc 2010). Families undergo twice-monthly group training sessions focusing on a wide range of topics chosen according to families' request (CASP n.d.). Lectures, typically delivered to a large group of up to 400 families, can cover topics ranging from behavior management techniques to dealing with sexuality to aging issues for people with disabilities and their caregivers. Large group lectures are often broadcast to a far-reaching international audience using interactive web conferencing software, enabling the audience to ask questions and participate in discussion activities.

Families also meet in small groups of 30-40 to work on their family IEP goals. Participants use these sessions to consult with CASP professionals and give feedback on programming. These small group sessions focus on three areas: learning behaviors that allow the family to treat their child like any other person, which is the basis of the CASP philosophy (Mayo et al 2008); developing skills families need to teach the child at home; and cultivating effective behavior management techniques (Mayo and LeBlanc 2010). Through the School of Families, parents and caregivers have a forum to ask questions, explore strategies, and problem-solve solutions together (Mayo et al 2008). Small group sessions are led by a team of CASP specialists and utilize activities such as role playing, demonstrations, and round table discussions as their primary teaching mechanism (CASP n.d.). CASP staff evaluate families' progress toward their family IEP goals and assign "homework" for the families to work on with their student. Likewise, families give feedback on the effectiveness of the specialists they work with and are given a forum to comment on their child's progress as well as their satisfaction with CASP programming (Mayo and LeBlanc 2010).

CASP and UIC partnership

Among other international partners, CASP has chosen to collaborate with the United States of America based University of Illinois at Chicago in Chicago, Illinois. For the last five years, doctoral students in UIC's occupational therapy department have participated in an advanced practicum experience, spending approximately four weeks at CASP. In addition to providing direct service for CASP clients, the OTD students act as consultants and educators for CASP staff and families. CASP does not hire a full time OT because of budget constraints and availability of local occupational therapists. They highly value OT input and, as a compromise, UIC plans to continue sending OTD students to CASP on a yearly basis (for as long as there is interest) to provide CASP with OT consultation and for student enrichment/practicum experience.

Upon arriving at CASP, the importance of partnering with families became evident. Parents and caregivers of CASP students were engaged and invested in most aspects of the student's education and inclusion in life. With this in mind, the authors emphasized collaboration with family, staff, and students in addressing needs in seating and positioning, feeding, household chores, ADL performance, and home and work site environmental adaptation.

Seating and positioning presentation

To illustrate this collaboration, the following section details the authors' efforts to address a need identified by CASP families and staff: improving seating and positioning. The authors developed a case-based lecture with an activity component to equip families and staff with the foundation knowledge to identify, evaluate, and resolve issues related to seating and positioning for function and participation. Because CASP does not employ an occupational therapist on staff, and because occupational therapy is not widely available to CASP families, the authors began the lecture with an overview of the profession and an introduction to

OT's role in seating and positioning for independence and participation.

The presentation then transitioned into the medical, functional and social benefits of proper positioning for students. The lecture covered key points for proper body alignment and positioning as well as environmental considerations, such as placing needed objects for a task within a person's reach and field of vision. Using case-based examples, authors encouraged participants to identify seating and positioning issues and problem solve possible solutions. Authors then helped families come up with simple, low-tech adaptations to accommodate students with a variety of needs, including high tone/spasticity, low tone, visual impairments, and neglect. To ensure the lecture was meaningful and relevant to the over 80 staff and family members who participated, cases were based on actual CASP students.

The lecture was followed up with an activity portion, during which all participants were invited to experience the various physical and environmental challenges faced by many CASP students. This was done by asking participants to attempt everyday activities, such as taking notes or playing a card game, while assuming positions typically associated with high tone or low tone to simulate motor difficulties many students face. To experience having visual deficits or field cuts, participants were asked to wear low-vision simulation goggles while performing an everyday activity. Participants were asked to comment on how it felt to experience these limitations. Many participants expressed surprise at how difficult simple tasks had become and noted their frustration at not being able to perform activities as they normally could. The authors then asked the audience to come up with possible solutions to compensate for these limitations. Finally, participants were asked to apply these principles to their child's daily routine. Families and staff were asked to think about what tasks the student might find difficult and brainstorm ways to make accommodations, either by changing the student's seating arrangement or some aspect of the environment.

Upon completion of the lecture and activities, families were given the chance to pose questions to the authors. To encourage participants' critical thinking and problem solving skills, the authors often directed these questions back to the audience. During these question and answer sessions, the authors were generally surprised by the ingenuity of the solutions presented by participants and the support they gave each other in the problem solving process. This effort to enable parents to act as problem solvers and change agents for their child is consistent with CASP's commitment to family empowerment. Encouraging participants to become skillful problem solvers builds capacity and lessens dependence on occupational therapists and other professionals, thereby promoting families' independence. By empowering parents to identify and resolve issues, the authors' work at CASP can be sustained beyond the scope of their physical presence at the center.

Conclusion

This rich involvement of families in the child's education is incredibly beneficial for staff, families, and especially students. Unfortunately, this kind of interrelationship is rare to see in the United States. Practitioners in the US and abroad, especially those working with pediatric populations, could learn much from CASP's use of the family empowerment model and School of Families training sessions. It is the authors' desire to find ways to integrate partnerships with parents and caregivers of persons with disabilities into day to day practice in the US, both in schools and other clinical settings.

As an occupational therapist in the outpatient rehabilitation setting, the first author encourages parents and family members to be present for all sessions. It is common practice in the pediatric outpatient setting to have families drop their child off for services and use the hour as respite time. Recognizing that although families and caregivers need a break, the caregivers' presence in the service provision for their child can impact the overall success and independence of their child exponentially and consequently decrease the overall burden of care. Caregiver presence in therapy sessions promotes a team like collaboration in which there is an open flow of knowledge and skills. This allows the therapist to foster a sense of empowerment within the caregiver by explaining the rationale behind activities and techniques used, determining ways to integrate strategies into the child and family's daily life, and problem solving issues occurring at home, in the community, and at school.

The second author is currently developing a program to assist Chicago families in learning to navigate the special education system and develop the skills necessary to advocate for their child's educational rights. Based on the success of the CASP model, the program is designed to foster communication and build partnerships between schools and families, emphasizing collaboration and mutual understanding for the benefit of the student. The program also seeks to promote families' independence and capacity to be powerful problem solvers and advocates for their child.

Through this mutually beneficial relationship between CASP and UIC, occupational therapy students and clinicians are paving the way to better collaboration with families. The hope is that the family empowerment and training models employed at CASP will provide a blueprint for increased family-practitioner partnership in the US and abroad, helping to create and sustain better occupational therapy practice all over the world.

For further information on CASP please visit: http://en.annsullivanperu.org

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Miembros
de la WFOT

X CONGRESO LATINOAMERICANO
DE TERAPIA OCUPACIONAL
V CONGRESO VENEZOLANO DE TERAPIA OCUPACIONAL

"Prácticas de la Terapia Ocupacional: Latinoamérica Construye e Integra Saberes"

26 de Octubre al 01 de Noviembre de 2013
CARACAS-VENEZUELA

Estimados colegas Terapeutas Ocupacionales:

Los invitamos a celebrar el X Congreso Latinoamericano de Terapia Ocupacional y el V Congreso Venezolano de Terapia Ocupacional en Caracas, Venezuela.

Estaremos enfocados sobre las diversas prácticas de la Terapia Ocupacional en Latinoamérica. Esperamos que este evento sea el espacio de encuentro para los Terapeutas Ocupacionales latinoamericanos y del mundo. Vean la página web para información sobre el envío de resúmenes de trabajos, posters y videos. Idioma: español.

Ejes Temáticos:
1. Lo filosófico, lo teórico y lo metodológico en Terapia Ocupacional. Ciencia de la Ocupación.
2. Impacto de las tecnologías de la información, la comunicación y las redes sociales sobre la Terapia Ocupacional.
3. La sociedad del conocimiento y la construcción del conocimiento en Terapia Ocupacional. Práctica Basada en la Evidencia.
4. Políticas de salud en Latinoamérica. Promoción y prevención en Terapia Ocupacional.

Programa General:
26 y 27/10/13: Reuniones de la CLATO (Directivos y Delegados) y Actividad Cultural.
28/10/13: VII Encuentro de las Carreras y de Docentes de Terapia Ocupacional Latinoamericanos.
29/10/13: Actividades Pre-Congreso.
30 y 31/10/13 y 1/11/13: X Congreso CLATO y V Congreso Venezolano de Terapia Ocupacional.

PÁGINA WEB www.congresoclato2013.com

La Escuela Virtu@l para Padres

Virtu@l School for Parents

Gabriela Verónica Pacheco
(Argentina)

Guillermo Pereyra
(Argentina)

Resumen: *La Escuela Virtu@l para Padres es un Proyecto de Extensión Universitaria de la Universidad Nacional de Quilmes (Buenos Aires, Argentina) que brinda servicios de capacitación para favorecer el desarrollo integral de la familia y la dignificación de la población, especialmente la más vulnerable. Su trabajo se desarrolla en forma virtual, presencial e interdisciplinaria, beneficiando a familias de toda Latinoamérica. Se trabaja en forma interdisciplinaria con organizaciones, profesionales, referentes y líderes comunitarios. Desea ser un espacio para el desarrollo profesional y académico de los alumnos y también una oportunidad de ser objeto para la investigación en el uso de herramientas digitales en la educación informal. Actualmente se trabaja elaborando contenidos multimediales de capacitación familiar y formando miembros de la comunidad como "Facilitadores de Escuela para Padres" a fin de favorecer la sustentabilidad, autogestión y multiplicación del proyecto en Argentina, Chile, Uruguay, Brasil, Bolivia, México, Perú y Colombia. Para más información visite www.escuelavirtualpadres.com*

Palabras clave: Capacitación familiar, Formación de Facilitadores, Medios Didácticos Multimedia.

Abstract: *The Virtu@l School for Parents is a University Extension Project of the National University of Quilmes (Buenos Aires, Argentina) that offers training services to help the holistic development of families and the dignity of the population, especially the most vulnerable. Its work is developed in virtual and classroom settings, incorporating the interdisciplinary involvement of organizations, professionals, role models and community leaders, benefiting families throughout Latin America. This teaching platform could also be used for the professional and academic development of university students and serve as a diagnostic tool for measuring the effectiveness of digital tools in informal education. Currently, progress is being made in the production of multimedia tools to train families, while members of the community are being trained as "School for Parents' Facilitators" to help the sustainability, self-management and expansion of the project in Argentina, Chile, Uruguay, Brazil, Mexico, Peru and Colombia. For more information, visit www.escuelavirtualpadres.com*

Key words: Production of multimedia tools, Training of facilitators, Training of families.

Introducción

El presente proyecto, la Escuela Virtu@l para Padres, se orienta desde la perspectiva de Terapia Ocupacional sosteniendo que la familia es el núcleo de la sociedad y se construye en el intercambio de todos los actores desde el rol que cada uno ejerce. La familia es el primer sistema al que pertenecemos, y como todo sistema tiende al equilibrio haciendo uso de múltiples mecanismos. En ella están implicados los más impredecibles altibajos, los que no se perciben como críticos, y aquellos que rompen con la estabilidad del sistema. La familia como institución tiene su propio organigrama, en la que los roles están claramente delimitados, o al menos consensuados entre sus integrantes.

El sistema familiar debe tender a la plena evolución de éste y al óptimo desarrollo de cada uno de sus miembros. Mutis, F. (2006) tomando a Minuchin (1999) nos dice que las funciones de la familia se orientan a dos fines: "Uno es interno, la protección psico-social de sus miembros, el otro es externo, la acomodación a una cultura y la transmisión de esa cultura".

Los sociólogos distinguen dos fases en el proceso de socialización de un sujeto, señalando que la primera de éstas sucede en el entorno familiar en el transcurso de los primeros años de vida. Esta etapa se caracteriza por la plasticidad para nuevas adquisiciones generando el sustento de aprendizajes futuros. "La familia es el principal agente socializador durante esta fase. El vínculo entre la madre y el niño subyace en muchos de los procesos de socialización primaria...." (Guiddens, A. 2001). La familia es cuna de afectividad, reciprocidad, contención, cooperación, estabilidad y permanencia vincular. Se demarca el guión paternal a la vez de promover la construcción del guión personal de los miembros.

Por intermedio de este proyecto se procura que los padres accedan a un espacio virtual o presencial en el que encuentren distintas estrategias que les permitan reflexionar acerca de su rol, manifestar inquietudes, tomar herramientas para aplicarlas en su encuentro diario con sus hijos. A la vez de inferirse que en el accionar en procura de alcanzar el más pleno desarrollo de una sociedad equitativa en el ejercicio de los derechos, es necesario que desde las distintas disciplinas se formulen propuestas emanadas de principios de calidad de vida, promoción de la salud y prevención.

Desde Terapia Ocupacional, se sostiene que toda persona está atravesada por las experiencias internalizadas a partir de los vínculos, constituyendo éstos el inicio de las experiencias sociales, motivadas por la necesidad particular del sujeto que a su vez lleva implícita la comunicación. Se sostiene también, que nada ocurre de modo único y aislado, que se está constantemente interaccionando con una serie de entornos que bien podrían facilitar u obstaculizar el desempeño de un sujeto. Los padres necesitan tener herramientas que les permitan revisar su aquí y ahora para afrontar sus situaciones particulares. Es preciso que logren identificar en sus entornos los factores que obstaculizan y/o facilitan el desempeño diario de su rol parental.

El terapista ocupacional intenta generar un recurso de acceso a las familias para su fortalecimiento, teniendo en cuenta la importancia de los vínculos y lo prioritario de la co-construcción de éstos en las etapas de la niñez y la adolescencia para la progresiva construcción de la identidad personal y ocupacional.

En esta propuesta para padres, se promueve la construcción conjunta de cada situación, siendo éstos los verdaderos conocedores de los entornos en los que desarrollan su cotidiano vivir. Se procura que los propios actores enaltezcan los recursos de cada sistema familiar y de la comunidad en la que están insertos, articulándolos como acciones concretas en la resolución de aquello que visualicen como amenazante o crítico.

Objetivos del proyecto y formas de implementación

El objetivo principal es brindar servicios interdisciplinarios de capacitación familiar en temáticas relacionadas a pediatría social, salud y educación en instituciones y grupos comunitarios, tanto en forma presencial como por medio de clases virtuales, creando contenidos audiovisuales, producciones radiales, gráficas y medios didácticos multimedia para su desarrollo e implementación.

Esta producción multimedial, se efectúa desde un enfoque intergeneracional y comunitario gracias a un trabajo colaborativo entre ancianos, hombres y mujeres jefes de familia, niños, docentes, miembros de la comunidad y de las instituciones implicadas.

Estos contenidos son utilizados como disparadores en los “Talleres para padres” que se organizan en instituciones para toda la comunidad en general, especialmente aquellas en situación de pobreza, exclusión y vulnerabilidad social. Desde su modalidad virtual, se fomenta la capacitación familiar procurando la participación e interacción de la comunidad a partir de variados canales digitales, actualmente a través de Facebook, del correo electrónico y por medio de videoconferencias utilizando Skype.

La Escuela Virtu@l para Padres, gracias a una alianza estratégica con instituciones y líderes comunitarios, brinda sus servicios a nivel regional. En todas sus modalidades de implementación, la Escuela Virtu@l para Padres, desea crear espacios de capacitación para la adquisición de habilidades en el desempeño de los roles paternos, creando oportunidades a las personas implicadas para reflexionar sobre su situación actual, desarrollar su creatividad y el pensamiento crítico en la resolución de conflictos.

Bajo la concepción de que cada sujeto intenta hacer frente a sus crisis de la mejor manera que le resulta posible, y que ocasionalmente el desconocimiento de estrategias o recursos ponen en riesgo su eficaz desempeño del rol parental, durante el período 2011-2013 se prevé llegar a las familias de todas las clases sociales trabajando en conjunto con instituciones educativas y O.N.G.

Actualmente dentro del equipo interdisciplinario hay 5 terapistas ocupacionales y 4 alumnos de la Licenciatura en Terapia Ocupacional de la Universidad Nacional de Quilmes que están involucrados en este proyecto desarrollando las siguientes funciones:

1) Terapistas ocupacionales junto a miembros de la comunidad coordinan encuentros con familias en instituciones.

2) Los terapistas ocupacionales elaboran clases virtuales y talleres presenciales para miembros de la comunidad acreditándolos como “Facilitadores de Escuela para Padres”, con el fin de favorecer la sustentabilidad, autogestión y multiplicación del proyecto en Argentina, Chile, Uruguay, Brasil, Bolivia, México, Perú y Colombia.

   El trabajo se organiza por medio de una plataforma virtual de aprendizaje, www.escuelavirtualpadres.com Allí, los facilitadores acceden a todos los contenidos multimedia a fin de organizar la capacitación a las familias desde la modalidad virtual o presencial y siempre en función de las necesidades, intereses y problemáticas observadas.

3) Diseño y elaboración de contenidos multimediales: los terapistas ocupacionales son entrevistados a fin de confeccionar materiales de capacitación familiar.

   Estas clases virtuales crean la oportunidad para el debate y siempre terminan con una **“actividad de aplicación”** para efectuar en la familia, a fin de aplicar lo aprendido en la capacitación. Aquí el papel del terapista ocupacional cobra mucha importancia ya que es el responsable de buscar acciones de implementación por medio de dichas actividades.

4) Los alumnos, coordinados por un terapista ocupacional, efectúan diagnósticos poblacionales a fin de conocer las necesidades y problemáticas de las familias de la zona de influencia.
5) Se implementa entre los terapistas ocupacionales el servicio S.O.S. Familia. Un servicio de ayuda online las 24 horas durante todo el año.
6) Los terapistas ocupacionales y alumnos de Terapia Ocupacional están elaborando guías de ayuda familiar en las siguientes temáticas: pediatría social, adopción, discapacidad, salud y educación.
7) La dirección de este proyecto está a cargo de un terapista ocupacional.

Generalmente, todo ciclo de capacitación incluye una charla acerca de la importancia del tiempo de juego en la familia. El juego como hacer, invita espontáneamente a involucrarse a partir de las propias motivaciones del sujeto. Se crea un escenario en el que convergen lo real y lo ficticio; el niño imagina, explora, especula en ese hacer. No tiene un fin distinto de obtener el placer mismo de jugar; es la ocupación por excelencia en la etapa de la niñez, no requiere de aprendizaje previo y es el medio potencial para el desarrollo. Asimismo, permite un mayor despertar de su imaginación y un mejor desarrollo de su creatividad; lo incita a descubrir y utilizar individualmente la inteligencia, la experiencia, el ambiente, su propio cuerpo y su personalidad.

El juego permite internalizar y exteriorizar vivencias, se ejercitan todo tipo de destrezas, se incorporan hábitos, se despliegan habilidades, se transmiten pautas culturales, se promueve la participación e interacción social. Se genera autoconocimiento, a la vez de conocer el mundo que lo rodea. La tolerancia a la espera, la frustración o la postergación, son algunos componentes modulados en el desarrollo del juego.

Las actividades lúdicas generan una instancia vincular, entretejen encuentros que propician la construcción de afectividad entre los involucrados, a la vez de la ideación del yo en el mundo, se conforma la identidad desde la mirada de los otros y la autopercepción de la participación con esos otros. El juego permite exteriorizar conflictos, deseos, ejercitar roles, ensayar la futura vida adulta. Por todo esto, el proyecto estimula y motiva a las familias a que empiecen a efectuar pequeños cambios en sus rutinas implementando “el juego del día”.

A partir de esta experiencia y a medida que continúan las capacitaciones, se observan cambios significativos en la vida de cada hogar.

Conclusiones

Por medio de este proyecto, la Terapia Ocupacional, en conjunto con otras disciplinas y con el apoyo de miembros de distintas comunidades, brinda soluciones prácticas a las problemáticas de la familia actual. La Universidad Nacional de Quilmes puede ofrecer a la sociedad las herramientas necesarias para abordar las necesidades familiares, creando múltiples espacios para el desarrollo de actividades preventivas.

Este proyecto funciona también como espacio para el desarrollo académico y la práctica profesional de los alumnos de Terapia Ocupacional y de otras carreras de dicha Casa de Altos Estudios.

Por todo esto, la Escuela Virtu@l para Padres es un espacio para el desarrollo de las familias, que busca generar en la comunidad a la que sirve, cambios lentos pero duraderos. Para más información, visite www.escuelavirtualpadres.com

Agradecimientos

A todos los terapistas ocupacionales, docentes, alumnos de la U.N.Q. y miembros de la comunidad que participan en este proyecto.

Prolcaf (Proyecto Latinoamericano de Capacitación Familiar).

Carrera de Terapia Ocupacional de la Universidad Nacional de Quilmes.

Secretaría de Extensión Universitaria de la UNQ.

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Nota: Si usted desea formar parte del proyecto o bien, que la Escuela Virtu@l para Padres articule con su institución, escríbanos a info@escuelavirtualpadres.com

Políticas y prácticas para el fortalecimiento familiar

Policies and practices strengthening families

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Resumen: *Este artículo presenta y discute la intervención del gobierno provincial y de la terapia ocupacional en su dimensión socio-política mediante el Programa Aleros (Santa Fe, Argentina). El mismo fue implementado en barrios populares con extrema pobreza, combinando apoyos asistenciales y promocionales de derechos para posibilitar la construcción objetiva y subjetiva del habitante como ciudadano. La ausencia de los umbrales básicos de calidad de vida (identificación personal, educación, salud, trabajo, protección social, seguridad, cultura, deporte y recreación, vivienda, medio ambiente e infraestructura, relación familia – comunidad) indican el grado de vulnerabilidad de los derechos humanos y la oferta de admisión de la familia al programa. El modelo innovador de intervención tiene como prioridad posicionar a la familia en el protagonismo de sus derechos implicando la transformación de las intervenciones típicas de los servicios estatales y de los profesionales, la formulación de estrategias reflexivas e integradoras, incluyendo a la familia en una evaluación participativa.*

Palabras clave: Derechos Humanos, Política Social, Servicios gubernamentales, Terapia Ocupacional social.

Abstract: *This article presents and discusses the intervention of the local government and occupational therapy in a social-political dimension through the program Aleros (Santa Fe, Argentina). This program was carried out in extremely poor neighborhoods, combining support and promotional assistance to enable an objective and subjective construction of the person as a citizen. Low basic standards of quality of life (identity, education, health, work, social protection, urban security, cultural life, sport and leisure activities, house conditions, home environment and infrastructure, family-community relation) indicate the level of vulnerability of human rights and therefore admission of families to the program. This groundbreaking model of intervention gives priority to the families as protagonists of their rights, involving family services programs and the development of reflective and inclusive strategies, including the active family evaluation by the family themselves.*

Key words: Human rights, social policy, government services, social occupational therapy.

Introducción

Esta presentación versa sobre algunas búsquedas, debates y propuestas surgidas desde la experiencia profesional como terapeuta ocupacional con familias en situación de pobreza en un programa denominado “Aleros”, implementado por el gobierno de la provincia de Santa Fe, Argentina, desde el año 2008[1]. Este programa, por decisión de la gestión política, se implementó primeramente en un barrio periférico del este de la ciudad santafesina, de características urbano-marginales (problemáticas medioambientales, deficiente infraestructura de servicios públicos, otros), identificado como uno de los más críticos y preocupantes para la agenda pública, en cuanto a la presencia de problemáticas relacionadas a la seguridad (trata de personas, hechos delictivos y homicidios) y al reconocimiento de la casi total ausencia de servicios estatales provinciales en dicho territorio.

Actividades socio-culturales y recreativas con las familias.

Descripción del Programa Aleros

El programa “Aleros” está basado en un enfoque de atención integral con apoyos asistenciales y promocionales a la población, cuyos derechos han sido sistemáticamente vulnerados, para posibilitar la construcción objetiva y subjetiva del habitante como ciudadano.

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[1] Santa Fe es la ciudad capital de la Provincia de Santa Fe y la novena ciudad más poblada de la Argentina. Está situada en la región centro-este del país, a orillas del río Salado y la laguna Setúbal. El aglomerado Gran Santa Fe, está conformado por 489.773 habitantes, de acuerdo a la Encuesta Permanente de Hogares.

En su diseño, a nivel territorial, se apoya sobre tres dispositivos: (a) el Consejo Territorial (C.T.), constituido como espacio de diálogo y articulación de los efectores del territorio (escuelas, centros de salud, entre otros) (b) el Servicio de Orientación Social (S.O.S.) compuesto por profesionales que acompañan a las familias en el proceso de fortalecimiento y de mejoramiento de su calidad de vida, favoreciendo la apropiación por parte de la población de los servicios gubernamentales instalados o a instalarse en el territorio; y el Edificio Alero, pensado para convocar a todo el grupo familiar, que aún no fue construido, por lo cual se utilizaron instalaciones existentes de la zona, para la implementación de las propuestas recreativo-deportivas y culturales.

La vulnerabilidad de derechos de la familia es lo que define su posible ingreso al programa, evaluándose cincuenta indicadores relativos a nueve umbrales básicos de calidad de vida: identidad, salud, educación, vivienda, medio ambiente e infraestructura, trabajo, protección social, seguridad, deporte, recreación y cultura, relación familia – comunidad.

Los profesionales del S.O.S. conformaron equipos de dos integrantes y cada equipo inicia, construye, sostiene y cierra el proceso de intervención con cada familia. La visita domiciliaria del equipo en los hogares, sin haber sido pedida por las familias en alguna agencia del gobierno, rompe con un estereotipo de la modalidad vincular de otras políticas y programas centrados en la demanda de la sociedad.

Fundamentos y supuestos *en* y *sobre* la intervención

Las familias despliegan estrategias de reproducción social[2] (Bourdieu, 1988), que son determinadas en parte, por el sistema de instrumentos de reproducción social disponibles, así las políticas sociales generan condiciones objetivas y subjetivas de vida. El programa Aleros impostó la relación gobierno –familia centrada en la promoción de derechos y secundariamente, en la asistencia económica. Esta política pública innovadora, no solo implicó resistencias y transformaciones en las familias, sino también en la hegemonía dominante del mismo sistema estatal y las propias prácticas profesionales.

Según Grassi (2003) el estado es el actor y el ámbito en la producción de los problemas sociales, delimita su propia responsabilidad, define a los sujetos merecedores de sus intervenciones y de las condiciones para dicho merecimiento. Con nuestras intervenciones podemos reproducir o re-construir criterios de evaluación – clasificación de requisitos - de riesgo y vulnerabilidad, categorizar las necesidades y potencialidades de las personas, administrar la admisibilidad de las personas a determinados programas, viabilizar o desestimar la adjudicación de servicios técnicos, económicos, otorgar la posibilidad de participación en roles ocupacionales y sociales, entre otros.

Reuniones informativas y de capacitación en emprendimiento asociativo productivo. Creación de lazos entre vecinos.

A su vez, en nuestra formación y práctica, pueden subyacer las corrientes de pensamiento de las ciencias que ubican al profesional como portador de un saber que le otorga poder. Contrariamente, en este nuevo modelo uno de los sostenes fundamentales es favorecer el protagonismo de la familia, sino *¿cómo promocionar derechos en la familia sino es con ella misma?*

La observación y las entrevistas en profundidad nos llevan a conocer, comprender e interpretar las trayectorias de vida, los recorridos familiares, sociales e institucionales, donde se opera para recuperar los aspectos vinculares y subjetivos dañados, a partir de la construcción de espacios de reflexión conjuntos. Comprender las historias de vida como un texto que se desarrolla en un particular contexto, permite aportar que estos grupos familiares vivencien una diferencia entre lo que venían trayendo en sus historias de vidas tan naturalizadas, contribuye a generar una ruptura y a partir de trabajar con ellos, problematizar esa ruptura, promover un proceso de recuperación de protagonismo en sus vidas para transformar su realidad y transformarse (Marmet, Aguirre, Alvarez, Pradolini 2011).

T.O. trata la vulneración de derechos de los sujetos mediante el análisis de los determinantes contextuales que los condicionan y el diseño de estrategias para su superación, implicando a la familia en “su” proceso. Se estimula, orienta, acompaña a la familia en la identificación de las potencialidades, fortalezas y dimensiones críticas, las demandas y oportunidades del contexto. El reconocimiento, validación, compartir lo que ellos tienen (su casa, su barrio, su tiempo, su historia), entre otras estrategias, intentan desestimar las incapacidades e imposibilidades de la sumisión a la pobreza. Analiza, moviliza y propone con la familia, las posibilidades de cambio y el desempeño necesario de todos para tales fines. La T.O. coopera con los sujetos en

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[2] Las estrategias de reproducción social se definen como un “conjunto de prácticas fenomenalmente muy diferentes, por medio de las cuales los individuos o las familias tienden de manera consciente o inconsciente a conservar o a aumentar su patrimonio, y correlativamente, a mantener o mejorar su posición en la estructura de las relaciones de clase”. En Bourdieu (1988) *La distinción. Criterios y bases sociales del gusto*. Taurus: Madrid, España. p. 122.

la identificación y práctica de las habilidades para asumir los roles de trabajador, ama de casa, estudiante, vecino (entre otros). De este modo procura el empoderamiento de los integrantes de las familias, mediante la participación ocupacional sostenida en el ejercicio de los derechos.

La valoración de las familias participantes

En el 2011 el equipo de trabajo planteó un estudio cualitativo para conocer: ¿Qué significaciones tienen las familias participantes acerca de sus dimensiones de calidad de vida? ¿Qué vínculos se pueden establecer entre dichas significaciones y el proceso de intervención del Programa Aleros? Se tomó una muestra aleatoria de seis familias que respondieran a diferentes criterios de inclusión cada una de ellas, de tal manera que se pudiera incorporar en la misma, la variabilidad de situaciones de abordaje tipificadas, como por ejemplo: cierre de intervención con objetivos alcanzados en 2010, cierre de intervención con objetivos logrados en 2010 pero con necesidad de reabrir el proceso en 2011, familia que haya participado de emprendimiento productivo, familia que no haya participado de emprendimientos productivos, entre otros.

Interpretando los resultados obtenidos mediante las entrevistas en profundidad, se formularon las siguientes conclusiones:

Las familias recuperan los cambios producidos en su vida cotidiana y en dirección a construirse como sujetos de derecho. Las personas entrevistadas reconocen al Programa Aleros y la actuación profesional como inéditos en relación a otros programas, en cuanto a: (a) el vínculo con equipo profesional, (b) visitas domiciliarias sostenidas periódicamente, (c) guía y acompañamiento en el análisis de problemas y posibles soluciones reconociendo sus propias posibilidades y las del contexto, (d) Identifican mejoría en algunas dimensiones de calidad de vida como trabajo, educación, seguridad, el espacio público, las relaciones intrafamiliares y comunitarias, por la responsabilidad de sus propias prácticas y las del Gobierno Municipal y Provincial. Y particularmente valoran positivamente que el profesional vaya a su encuentro, sostenga el vínculo en el tiempo, escuche y acompañe tal proceso de cambio.

En el proceso de implementación del Programa y sus resultados, del 2008 al 2011, se valoran cualitativamente los indicadores de calidad de vida que han podido ser mejorados. Hay algunas dimensiones que no son evocadas por estos grupos familiares entrevistados, lo que probablemente se fundamente en que no son consideradas prioritarias y no figuran entre los problemas principales a resolver según sus criterios, aunque formaron parte de los aspectos trabajados con ellas.

Este estudio permitió detectar un aspecto implícito pero de importancia en la valoración de los objetivos del Programa: las entrevistadas resaltaron la importancia de los cambios en el grupo familiar, relacionándolo pero a la vez y en segundo lugar resaltando la acción del equipo y haciendo eje en sus propias capacidades y posibilidades.

Conclusiones

Se logró generar en lo posible, propuestas de abordaje desde la integralidad, lo que a su vez produjo cambios y adecuaciones permanentes en las modalidades de intervención, tanto en las instituciones como en los grupos familiares abordados (700 aproximadamente en cuatro años). Así, también las instituciones del Consejo Territorial se fueron "abriendo" a una nueva forma de comprender al grupo familiar y sus miembros, pudiéndose operar algunos cambios al interior de las mismas y aportar al mejor desarrollo de sus tareas.

La intervención supone la co-construcción de estrategias que fortalezcan a las familias en su protagonismo: habilitar, acompañar, implicar-nos en las decisiones y acciones de análisis de problemas y resoluciones de la vida colectiva.

La T.O. desde su especificidad en un abordaje transdisciplinar contribuye a la promoción de condiciones y oportunidades que acercan a la población a las dimensiones de calidad de vida.

Si toda práctica profesional también es una práctica socio-política (Guajardo y Kronenberg 2010), estamos éticamente comprometidos a reflexionar sobre el lugar que vamos ocupando, el sentido y la proyección de nuestro hacer, en qué medida reproducimos y/ o transformamos lo que se intenta cambiar.

Agradecimientos

A las familias por su confianza y apertura. A los compañeros y compañeras de trabajo por el diálogo, el debate y la cooperación. Y a todos los que me permiten trabajar y aprender juntos.

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Together we can! Working with family and caregivers of children with developmental disability

Abstract: *The article discusses challenge while working with family of children with developmental disability [CWDD] in India through case studies. The text includes the interconnections between the use of evidence and creativity of the occupational therapist to minimise the interference of context in the therapeutic process. Working with families of CWDD needs thorough consideration of the client, the task and the context. The text highlights the ways in which clinical decision making is tailored to clients' and contextual need to gain best outcomes through therapy.*

Key words: Family centred care, children with developmental disabilities, carers.

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Introduction

India has been crowned as the country with second highest population in the world and is the world's largest democratic country. It is a country with a rich variety of culture, language and beliefs, renowned for its festivals, people and hospitality.

This multi-cultural and multi-lingual asset proves a challenge for an occupational therapist when he/she has to work with clients and their families from various socio-cultural backgrounds. It can be like building a bridge between two different cultures, one of therapist and the other of the client. The language, the beliefs, the socio-economic background, significant others in the family all influence the outcome of the therapeutic process for CWDD.

This article mainly covers work undertaken in the suburbs of Mumbai, the capital of Maharashtra State, India. The official language of Maharashtra is Marathi. Being a metropolitan city, there is a wide array of languages spoken. The preferred language for communication remains Marathi and Hindi. In the suburbs, the population comprises of lower middle class to upper middle class. The family structure is joint family where 5-8 people share an apartment. The apartments are usually made up of cement with smaller rooms.

There are mainly two systems of services where clients can avail occupational therapy, one being at the institutional level and the other being home-based rehabilitation. The institutes range from public to non-profit organizations and private clinics. None of the services are covered by insurance companies. Services are offered freely at public set-ups and to a greater level subsidised at non-governmental organisations. The cost of services varies in private centres and home visits which are often expensive.

There are multiple issues which hinder clients from seeking benefits of occupational therapy in India. The greatest challenge is the negative ratio between practicing therapists and people in need of therapy, the sparse distribution of set-ups, economical liability, socio-cultural norms and acceptance of conditions, disabled unfriendly community and pit-falls in government policies.

Family centred practice has been in recent years deepening its roots in India.The benefits are slowly and steadily supporting the day-to-day practice in occupational therapy. Occupational therapists use scientific knowledge and creativity to strike the balance between evidence-based practice and family expectations, combating the challenges posed by the variable contexts. Keeping current evidence in focus the therapist changes media and methods to fit the cultural perspective of the client.

This article focuses on the effortful yet rewarding process of working with the families and care-givers of children with developmental disabilities at therapy clinic and in home-based rehabilitation.

Developing phase of partnership

The referrals for therapy come from practicing medical professionals, occupational therapists from other localities, schools, interviews on television, awareness campaigns or even through word of mouth from other clients.

The first interview usually begins with seeking information and assessment of the various components, occupational areas and context. During this process it requires the therapists' skills to gain access to the family's beliefs and ideas and to draw relevant conclusions. Verbal and non-verbal communications play a vital role in developing relationships and strong bonds.

It is of prime importance to master the relevant languages and the accent. The comfort of speaking in the clients' language establishes a strong therapeutic alliance. Most of the clientele would prefer talking in Marathi/Hindi. Therapist must be well versed with the colloquial terminologies for specific scientific words, for example disability is called *"Adhu"/"Vyang"*; Brain is called as *"Dimag"/"Mendu"*.

The experience of the therapist is another factor which helps in the clinical reasoning related to assessment and forming ideas about the client and the family. Therapists, in daily practice encounter carers who feel more comfortable speaking with senior therapists than with novices. In such cases appropriate field notes and case discussions help in communicating important information.

The approach in India is empathetic. During the first visit, using the greeting *'Namaste'* by joining two hands together is considered a mark of respect. In the home-based set-up, removing footwear outside the house and sitting with the child and family on the floor rather than across a table is considered to be culturally appropriate and develops a good rapport. The role of therapist is to inform the family about the condition of the child, the possible options for therapy, the technicalities, the prognosis and the expected participation from the family members, in a manner best understood. It is a new concept to the parents to get involved in their child's therapy. Most of them have been brought up with the notion of "Doctor proposes and client disposes". They find it surprising and sometimes even a challenging experience to make conscious decisions regarding therapy together with the therapist.

The therapist needs to deal with a few scenarios without being judgemental, e.g. if a mother who has sought divorce because of the child being disabled, comes to seek service. Similarly, sensitive issues like alternative medicines, faith healers, and rituals have to be considered with utmost empathy and understanding.

The therapist needs to be acknowledging emotional needs at times in regards to caregivers, mostly mothers who sometimes have emotional overlay during interviews. Therapist should also try to seek information regarding the carers and responsible members of family who shall be participants in the therapy process. In India, though mothers are usually the primary carers, siblings, family friends, cousins, and neighbours also sometimes share the responsibility. The social circle remains strong in the community structure in India. For example, SL, a 2 years old CWDD is escorted by his grandmother since both his parents are employed. The grandmother is minimally literate and feels it difficult to comprehend the procedures like stretching spastic muscles and donning-doffing of orthosis. The therapist communicates to parents through written note or telephonic conversations. On the other hand, YP, a 15 year old CWDD is accompanied by her elder sister who actively participates in the activity regime.

Shared decision making

In public or non-governmental organisations the majority of population seeking services are those who are poor and illiterate. While formulating the therapy program, the therapists has to use simple language to explain the process, the participation anticipated, the temporal aspect of the condition and expected outcomes from therapy. The therapist needs to be skilful in evoking effective participation by supporting views, acknowledging efforts by the carers, delineating the follow up of the program.

It is indeed a challenge to formulate an individualised therapy program for clients of different ethnicity. The available evidence is based on mostly western cultural context and less through an Indian perspective. It is the strong ethical reasoning that helps therapist to implement a client centred therapy.

Use of available material is one such consideration. Use of readily available sand bags as a substitute to weighted cuffs, use of writing slate for handwriting training, use of clay/dough to make a gripper, use of cut-out wooden chair as a substitute for Indian style toilets, swings made up of 'sarees' [Indian women attire which is 6 meters long draped around the body] to provide vestibular inputs, use of wooden cane for gait training, use of Bollywood dance numbers or songs than nursery rhymes as a positive reinforcer are a few illustrations which therapist have to be aware of.

Making decisions regarding change in environment is done on the basis of interviews or home visits. The houses of the clients are small and therefore most of the time do not accommodate the use of high-tech/large modifications. Use of a foldable wheelchair or adjustable CP chair which fits the available space, rearranging furniture, use of towel rolls to reduce hip adductor spasticity are a few such considerations.

A series of discussions need to be done before arriving at a particular conclusion regarding the prescription of a device or a tool.

An 8 years old client, AG, presenting with diplegic paralysis, attends regular schooling. AG has loss of vision in one eye due to forceps delivery. He finds it difficult to read text from textbooks provided by school. The therapist had to help parents to approach the local education authority to avail books with larger fonts which are available but less known.

People in India have a bath everyday as a ritual. Bathing involves use of soap and bucket of water rather than the use of showers and shower gels as in western culture. AG had difficulties in holding soap while bathing himself. The therapist used a circular shaped comb with the handle to pierce it through the soft soap so that AG could secure his fingers and carry out the procedure with ease.

OB, a 5 year old CWDD, has generalised hypotonia and poor speech development. His mother expressed the wish to initiate something new on his 5th birthday. The therapist in discussion with his family suggested OB to be admitted to a play group with his CP chair being made available at the school. The school teacher was briefed about him by the therapist and was helpful in admitting OB to the school. The 'Team' considered it to be the best Birthday gift for OB who enjoys his school time a lot.

Empowering carers

The major challenge to reach out to CWDD is the availability of therapists and their sessions. Therapy sessions are seldom arranged on a regular basis considering the constraint on available time slots. In such scenario it becomes essential for the therapists to train the carer to take charge of the therapy at home.

SG is a 7 year old child with cerebral palsy (CP) residing at interiors of Maharashtra State, seeking therapy at an NGO located around 5 hours of travelling distance by public transport. He is seen once in a month by the therapist. The therapist writes down the entire program in a comprehensible language and demonstrates the exercises and techniques like oromotor training, gross and fine motor exercises, to the parents who then carry it out at home as a part of the home program. SG has shown improvement in terms of reduced drooling, better balance and started writing alphabets in school after 3 months follow-up. The parents expressed the sense of victory to have seen change in the child's condition.

Working with such a model saves the economic burden on the family by cutting cost of travelling. Another way to conduct such training is the formulation of workshops for carers delivered in a language best understood by them. Audio-visual presentations, live demonstrations, hands-on training, are all included as a part of such programs. This helps to reach out to many families at one time, solve common concerns and also save time to address such issues individually.

A group of parents of children with spastic CP, seeking therapy in clinic, were selected for a workshop to address concerns regarding importance of maintaining ADL routines, positioning and developing play skills. Parents then gave the feedback of having gained more knowledge and found it easier to carry out these suggestions effectively at home.

Family as the focus of intervention

SP is a 5 years old CWDD. Her mother is the sole carer and is a homemaker. SP's father died in a mishap while he was in public service. Though the compensation given to her fulfils her economic concern, the mother suffers from feeling uncertain about SP's future for this mother, being enrolled in a peer parent support group has helped her to cope with her anxiety. Identifying families with similar challenges and helping them to form support groups therefore becomes of utmost important.

OB's mother is a primary carer and has been diagnosed with lumbar disc prolapse and hence, finds it difficult to carry him while taking him to school. The occupational therapist was assigned to treat OB, had to also implement back care exercises for his mother to relieve her pain and work in designing a modified kangaroo bag to carry him to school.

Mothers mostly are the primary caregivers for CWDD. They experience immense social disengagement, isolation and poor self-esteem due to the multiple roles that they have to play as a carer for CWDD, their family and other siblings. Therapist has to be vigilant about the carers and should address their concerns from time to time.

Continuing alliance

PB, an 8 years old girl presents with hemiplegic cerebral palsy. She attends regular schooling. After 2 years of regular occupational therapy, PB had shown remarkable improvement in terms of motor and perceptual skills and thus, was discharged from the regular therapy sessions. She is well adjusted in the school and the family now has minimal concerns regarding her motor skills. The parents wish to keep in touch with the therapist from time to time to seek suggestions about speed of writing, play skills, and social skills behaviour. Such consultation happens once in 3-4 months.

Many a time, clients from other states/district places are referred to local therapists/community workers, to curtail travel expenses and inconvenience. Therapist assists in finding resources in the clients' vicinity which is often challenging task in some resource poor places in India.

Recently, technology has brought positive change in India. Therapist now exchange ideas and seek suggestions through emails, by being a part of social networking websites like 'Facebook' or 'Twitter', and creating one's own blog or web site.

Bonds beyond therapy

Occupational therapists in India usually share a long standing bond while offering intervention for CWDD. It is not uncommon for a therapist to get invited for family functions, festivals and birthday parties. Therapists become a part of their extended family. It is a skill of the therapist to often associate and dissociate in situations. Balancing ethics and ethnicity requires due emotional maturation and expertise.

Activities beyond therapy session include organising special programs like annual day celebrations, arts classes during festivals, get-togethers and picnics. This helps provide family with positive feelings and equal opportunities for CWDD.

Amalgamation of the efforts of working with diversities into a better tomorrow for our CWDD is what makes the journey worthwhile for therapists!

Conclusion

Implementing occupational therapy in the Indian cultural background is challenging since most of the literature that is available and textbooks that are enlisted in the occupational therapy course syllabus are based on western populations. The focuses are being more cost effective, use low cost aids, and develop a disabled friendly community. Awareness about the field of occupational therapy still needs to be enlightened.

Working with clients in India needs more than just knowledge about the science of occupational therapy but also the art and creativity of implementing the program and overcoming socio-cultural barriers. Therapy should reflect consideration for the clients' capability, expectations of parents, and positive reinforces from the environment for it to be effective.

Occupational Therapy practice in India can provide an illustration to other Asian countries which are similar challenges of diverse population, lack of resources and professionals where empowering families become prima foci.

The collaborative and customised approach with clients and their families leads to better outcomes of the therapeutic process and can be easily translated into occupational therapy in other countries around Asia and globally. **Together we can surely make a difference!**

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Overcoming illness and disability issues within the home setting: a case example

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Abstract: *Using a real case example, this article demonstrates implementation of occupational therapy approaches for professionals who are aiming to meet a family's needs facing a deep crisis generated by illness and disability. Recommendations include the need to be sensitive to the family's ability to absorb the changed circumstances which affect the whole family, providing support to the family through acknowledging and supporting the family's efforts throughout the recovery time. This includes the emotional, informational and practical supports which should be given constantly and empathically right from the hospital to the home transition and long-term rehabilitation care.*

Recommendations were made for an educational program for families in hospitals to support the home transition and disability management. These recommendations support a family centred educational approach with an emphasis on care and empathy not only for the person with disability but for all family members as they attempt to come to terms with the new situation and cope on a day-to-day basis with new circumstances.

Key words: Family, home-based intervention, family-centered practice, educational approach.

Introduction

On an ordinary day an ordinary family is suddenly thrown into deep crisis, physically, socially and emotionally when the family's breadwinner and father of three children undergoes a life-threatening brain tumor surgery. After two months of hospitalization and rehabilitation characterized by fear, confusion, anger and struggle with uncertainty, the family takes home their loved one who no longer talks, does not move or react and moreover has a feeding tube in his stomach. Without much encouragement from physicians in terms of recovery and without reliable professional assistance from community social services, the family is feeling worried and weak, has to face an extremely difficult problem created by the delicate future condition for their paralyzed, dysphasic, incontinent, confused and aphasic member.

It is a daily reality for such a family, living in a developing country which is dealing with unceasing reforms and transition in the field of services provided for people with disabilities. This family required home-based intervention which the occupational therapist provided consistently and continuously over the past three years (2009-2012) with very practical and concrete actions for solving problems in the care and wellbeing of this very severely impaired person.

The occupational therapist, in the effort to ***gain trust and acceptance*** of the "immediate" family, was challenged professionally, personally and culturally. The family's trust and acceptance were revealed to the therapist when specific suggestions and recommendations made about illness management and environmental adaptations were "followed through with the treatment plans suggested" (Tomlinson 2004, p. 678).

Health care in Romania

«The Country Cooperation Strategy briefs» of W.H.O. updated in May 2011 and «the new draft of the law on health system in Romania» subject to public debate in July 2012 indicate that the Ministry of Health is the central authority responsible for organization, development, finance, data collection and functioning standards for public health institutions, national health programs and reports on the population status. The current public health care services are delivered at three levels: the primary level of care assigned to family doctors, dentists and pharmacists; the secondary level of ambulatory care assigned to specialist doctors practicing in hospital outpatients departments, centres for diagnosis and treatment and office-based specialties; the tertiary level of care assigned to doctors practicing in hospitals inpatients departments. The home-based health care and recommendations for medical rehabilitation and social services for people within the community are integrated into the practice of family doctors. Home-based therapies are normally provided by non-governmental organizations and independent practitioners operating from their own offices.

The numerous reforms introduced since 1989 mean that many people have limited and inadequate access to health care services due to the formal (co-payment) and informal payments at the point of use.

The impact of the family functions model on home-based occupational therapy

Some literature examining the relationship between family's function and behavior and the effectiveness of delivered health care services toward patient/client recovery indicate several implications for home-based occupational therapy (Boyce et al 2000).

Occupational therapy services within the natural home setting requires the therapist's understanding of values, codes and "ideology" that guide the family response to life events. The OT helps the family to gain a better insight on adequate service options ranging from direct intervention and collaboration, to counseling and training new skills (Case-Smith and Cable 1996). Secondly the ***educational approach*** is recommended for all family-based services in Romania where the interventions support the family adjustment to the altered relationship with the ill and dependent member. The identification of small rewards in a context of a smile of appreciation or eye contact for example is considered a "form of reciprocation ... as a natural element of social relations" in the educational approach (Tsouna-Hadjis et al 2000).

Another implication on home-based occupational therapy practice is the ***collaborative approach*** where "shared responsibility for concrete actions generates flexible and creative solutions to problems" (Idol et al 1986). This collaborative work is the core of the client-centered practice concept underpinning the occupational therapy profession (Blain and Townsend 1993) and the approach within the framework of this case example.

Life-experienced case example

Family history

The family of a priest consisted of 5 members: the ill husband, the wife, and three children aged between 17-24 years old, living all together in a big house. The family, well educated both in a religious and in academic spirit, focuses and directs its "source of ideology": values, interests, activities, emotional investments, needs and expectations toward the family and the church. The illness condition and its consequences on the family routine and social life highlighted and strengthened the family love and faith. Its "source of ideology" was identified through observation, interview and use of the Functional Independence Measure/FIM (Ottenbacher and Christiansen 1997, pp. 117-120).

The intervention was fully addressed and adjusted to the environmental demands in the natural home environment by the rehabilitation team including the occupational therapist, physical therapist, speech-language pathologist, and psychologist.

Patient's safety and home care

With training and experience in physical disabilities and psychosocial issues, the occupational therapist used an educational approach to address successfully over time the family's concerns and fear about the benefits of sensory stimulations, physical movement, social visits and changes in family behavior around their disabled member. The family response for their member's safety changed so that at present, dinner time gathers all the family members, able and disabled, at the kitchen table every evening.

Environmental accessibility and assistive equipment

Typically for many severely impaired individuals whose personal ADL are carried out in bed and/or in wheelchair the occupational therapy intervention combined the compensatory with the re-learning approaches. Home modifications, choice and use of assistive equipments, appropriate handling and transfer techniques aiming to ease the caregiver's physical and emotional involvement in personal self-care activities were identified by the occupational therapist by means of observation and interview. Improved indoor safety and accessibility along with wheelchair mobility allow the disabled member to have the shower and grooming in the bathroom, to participate at family meal times and social events in the living room, and to enjoy a sunny day on the terrace.

Managing care in a home environment

Care for people with dysphasia required a direct treatment approach. The occupational therapist used an intervention program focusing on learning about positioning, skin care, handling, food texture and liquids intake, paralysis, wheelchair transfers, and family behavior to visual impairment, body neglect and perceptual deficits, as well as daily routine adaptations in an ergonomic approach for the caregiver 'safety and health condition.

Social-emotional eccentricities and sensory processing problems

The occupational therapist clinical experience in understanding of behaviors related to sensory integration problems (Wilbarger 1991) allowed for a valuable and intensive treatment approach to tactile, oral-motor, and auditory defensiveness visible through challenging behavior: biting, pinching, rubbing, screaming, and stereotyped movements. The disabled member's awareness, finger feeding, drinking, eye contact, reaching for objects and functional communication abilities (gestures, sounds, facial expression and few words) were improved by the use of brushing program, deep pressure, oral massage techniques before feeding, clothing texture adjustments, and the use of reduced tone of voice.

Motor skills

Using the standardized FIM test (Ottenbacher and Christiansen 1997) for ADL assessment in correlation to the biomechanical frame of reference for the functional observation (Latella and Meriano 2003) of the disabled person's bed mobility and eating activities influenced the occupational therapist and physical therapist's collaborative decision regarding the goals for intervention. By the end of two and a half years using the restorative physical program the disabled member's progress in head mobility and control as well as in trunk stability allowed him to put on socks, shoes and tie shoelaces with left hand while sitting with his back supported. His paralysis and spasticity, ineffective and reflex movements, protection of the impaired extremities, and orthostatic hypotension were also addressed by educating and training the family in appropriate handling and transfer techniques.

Incontinence

Bowel and bladder management together with a nutritional diet were the issues completely handled by the wife. She used all her knowledge and skills acquired as a mother, a person who has nurtured and raised three healthy children as well as concurrently being a pharmacist. She allowed no one else to support or assist her in these management issues.

Challenges for the occupational therapist

A recent discussion with the wife, the family "stakeholder", about the last three years experience revealed to the author that ***gaining trust*** was much more easier than ***acceptance***.

The therapist's reliability and punctuality but especially her attitude and her certainty in approaching the disabled member's condition proved sufficient to garantee the occupational therapist professionalism and the family's trust over time.

Constantly acknowledgeing the efforts the family in caring and assisting the disabled member was the key to acceptance. Supporting the disabled member's condition more than the family pre-illness and after-illness history proved to be detrimental to short-term positive results. The therapist made a great effort to manange through the established treatment plan to have the first visible functional outcome. Only discussing beforehand with the family the needed changes and techniques and giving the time for "thinking" may enhance a more efficient partnership with the immediate family members.

With the above professional challenges, the occupational therapist was given the opportunity to deal social-culturally with the "medical model" way of thinking about a disabled person and his family. Negatively internalizing the diagnosis and the "handicapped with severe degree" label written in the documents, the family was challenged day-by-day by the therapist's occupational perspective in managing efficiently the person's disability at home, and in encouraging and assisting the disabled member's participation in family life.

From the personal point of view the greatest challenge was to sense in all those years the family's outstanding love surrounding their disabled member and their spiritual commitement while struggling with social marginalization and limited community resources, and still solving problems encountered in daily life activities, the therapist's job requirements and professional development.

In this situation, the wife of the disabled family member made a few recommendations for professionals who are aiming to meet a family needs facing a deep crisis generated by illness and disability. Firstly, she felt that the results of the initial assesment should not be immediately shared with the family. It is not sensitive to the pre-illness situation and does not helps the family to remind past achievements, validate self-image and the ability to stand firm. She noted that the family must be provided with a lot of emotional support by ackowledgeging their efforts over the recovery time. She noted that the emotional, informational and practical supports should be given constantly and empathically right from the hospital to the home transition and long-term rehabilitation care. She suggested that there should be an educational program for families in hospitals to support the home transition and disability management. These recommendations support a family centred educational approach with an emphasis on care and empathy not only for the person with disability but for all family members as they attempt to come to terms with the new situation and cope on a day-to-day basis with new circumstances.

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You're in Charge: an innovative intervention program for families with adolescents with chronic illnesses

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Abstract: *The transition from pediatric to adult health services is frequently experienced by families and youth with chronic illness as stressful, poorly planned and lacking in preparation. Many literature reviews and empirical studies have been conducted to enhance health care providers' understanding of best practice in the area of transitions, and yet the perceptions of youth and families continue to indicate improvements are needed. This paper describes the development of an innovative, early preparation program for young adolescents with chronic illnesses and their families in Canada. Occupational therapists have been instrumental in guiding this development to reflect current theoretical and empirical evidence in transition and chronic disease self-management. Data from the early stages of implementation of this program are presented. Future directions for research and practice are also described.*

Key words: Youth, transition, self-management, chronic conditions.

Introduction

Adolescents and young adults with chronic illnesses are a growing constituency of health care consumers (Crowley et al 2011). Adolescents and young adults bring a unique perspective to health services and can be powerful advocates for changing our healthcare system (Malla & Norman 2001). Many young people with chronic illnesses are surviving into adulthood and face the challenge of assuming responsibility for their complex health care needs. These young people frequently need to negotiate the transfer of care and shift in responsibility for health related decisions with their families as well as their health care providers (Sansom-Daly et al 2012). Given the usual challenges of the transition to adulthood in all areas of development, adolescents and young adults with chronic illnesses have additional burdens in navigating a positive trajectory toward productive occupation, meaningful engagement and successful adulthood (Crowley et al 2011, Mennito & Clark 2010).

There is an expanding body of empirical literature that examines this phenomenon. Much of the literature is located in studies that focus on the transition or transfer of care from pediatric to adult health care systems. Scholars from many disciplines have examined interventions, developed measurement instruments, as well as proposed theoretical frameworks and conceptual models to increase our understanding of this complex experience. Issues of transition have been described and interrogated using qualitative, quantitative and mixed methods in psychology, sociology, health disciplines and education. Occupational therapists have contributed to this body of knowledge. However, the area of transitions is not usually conceptualized as having an influence on occupation. To address this gap in the literature, Stewart (2013) has recently published a text that does address this transition experience with an occupational therapy lens. It appears that while there is still much to be learned about best practice for transition, a focus on the person-environment-occupation interaction may situate occupational therapists as leaders.

This paper will present an innovative, new program that provides interventions to assist families with young adolescents with chronic illnesses. Specifically, the program targets those families who are just beginning to address and prepare for the transition from pediatric to adult health care services. "You're in Charge" draws on evidence from the broad fields of health care transition and the chronic disease self-management literature. The intersection of these two fields of research provides fertile ground for innovation and the development of potentially efficacious best practice. A brief review of the recent literature in both fields is presented. The current state of the transition intervention programming in Canada is then described to set the stage for the impetus of the "You're in Charge" program. The evolution of the program through its first three years of operation is then presented to demonstrate the refinement of the program in response to the evaluation findings. Finally, the implications for practice and future research are discussed.

Transition of adolescents with chronic illnesses into adult health services – current literature

As stated earlier, there is a rich body of empirical literature about the transition from pediatric to adult health services for adolescents with chronic illnesses (Crowley et al 2011, Schwartz et al 2011, Wang et al 2010). All scholars describe this transition as complex, involving multiple systems such as health, social services, education and employment. Adolescents simultaneously experience transitions in all these systems, which magnifies the complexity. Much of the empirical literature that has examined transitions in health care has focused on the knowledge and skills that adolescents lack as they transfer from pediatric to adult care (Schwartz et al 2011). Several studies have identified that families, specifically parents, play an influencing role in this transition but few studies have examined transition in a way that accounts for the systemic influences such as culture, government and policy (Crowley et al 2011).

Wang et al (2010) identified that a limitation of the empirical work conducted on transition has been the lack of theoretical frameworks or conceptual models to guide the development of intervention and measurement in this area. Only 10 of the 46 studies included in this review had identified a theoretical framework as part of their work. The authors proposed the implementation of Bronfenbrenner's Ecological Model (1979) and mapped the findings from the 46 studies on transition to this model as a way of illustrating its explanatory potential. Wang et al (2010) recommend that interventions for transition could target all levels of the ecological model and that multiple targets were likely to be most effective.

Building on Wang's work, Schwartz et al (2011) also acknowledged that while there have been a plethora of consensus statements and policy oriented papers focused on transition, there is a lack of theoretical and conceptual work that could drive the development of clinical practice guidelines, measurement instruments and intervention manuals to support the systematic examination of transition and the development of best practice guidelines.

A social-ecological model focusing on the interplay of knowledge, skills, self-efficacy, beliefs, goals and relationships between patients, their families and their health care providers was proposed by Schwartz et al (2011). Skills and knowledge are still recognized as important facilitators of the transition process. However, skills and knowledge for the adolescent alone will not result in successful transitions if the patient is not motivated, developmentally ready, supported by family to follow-through, or if the health care system is not ready to facilitate the transition.

Patients, families and health care providers must all be in a state of readiness for success to ensue. Adolescents need to develop self-management skills, parents need to support this self-management and health care providers need to facilitate the negotiation of this shift in responsibility. Recent research looking at specific determinants of successful transition highlighted the importance of positive attitudes towards transition and high levels of self-efficacy regarding ability to manage self-care tasks (van Staa et al 2011).

Chronic disease self-management for adolescents – current literature

In the early years when a child has a chronic illness, parents and health care providers act as the primary caregivers and decision-makers. Information and negotiations about client care are often presented to parents who ultimately make decisions about what they feel is best for their child (Mattosinho & da Silva 2007). Decision-making authority shifts away from parents when youth transition to adult health care services. As a result, this presents as a point of contention in optimal care as the young adults may not be well versed in their own medical status. Therefore, a gradual increase in self-management and decision-making on the part of the youth will result in an increase in self-efficacy, psychological well-being and more positive transition outcomes (Crowley et al 2011). Facilitating self-management throughout the transition process can result in positive effects not only for the patients but also for the future of health care as a whole (van Eijk & de Haan 1998).

Having a chronic disease as an adolescent impacts on participation in activities, roles and relationships. The need to carry out complex medical routines may affect their ability to respond to the spontaneity of adolescent activity. Others may have restrictions in their capacity for employment or post-secondary education. However, almost all will face the need to cope with overwhelming emotional and psychological consequences that impact on their relationships with parents, siblings and peers (Versnel 2011).

Adolescents with chronic illness do not always acquiesce to the controlling tendencies of their parents and health care providers. Most do learn to get more involved in the management of their own health care needs but the path of that involvement is not well understood and it does not appear to mirror how adults learn to self-manage their health needs as they age (Sawyer & Aroni 2005). Many adolescent-oriented health care transition programs embed elements of self-management skills within the context of transition. However, not all transition programs involve families and in the early preparation for transition, parental participation is vital (Versnel 2011).

In recent years, there has been a concerted effort in Canada to develop evidence-based transition programs for adolescents with chronic illness and childhood onset disability. A recent paper by Fletcher-Johnston et al (2011) described a study conducted to identify pertinent research priorities in adolescent healthcare transitions and develop a framework for an ongoing program of research. One hundred and fourteen Canadian clinicians and academics were invited to participate in this national study. Identified priorities included: skills and knowledge adolescents require for the transition process, how to measure success, determining the factors that influence a successful transition and whether good transitions improve health outcomes. The next section of this paper describes the current state of evidence regarding transition/self-management programs in Canada.

Transition/self-management programs for adolescents in the Canadian context

In recent years in Canada, several new initiatives have provided innovative ways of conceptualizing frameworks and models that guide the development of transition services. One of these models has been empirically tested, the Life Needs Model (King et al 2002, 2006). A second framework, Growing Up Ready (Gall et al 2006) has also been described in the literature. Transition programs developed in Canada including Youth En Route (Evans et al 2006) and Best Journey to Adult Life (CanChild 2009) have undergone various types of evaluation and these have been reported in the literature. Findings from these preliminary evaluations indicate both of these programs show promise as interventions to prepare youth to transition to adult services.

Grant & Pan (2011) identified and compared additional transition programs for youth with chronic illness in Canada. On Trac (Paone 2000), a transition program from British Columbia is the longest in existence, initiated in 1998. On Trac is a model of transition care that is integrated in to the multidisciplinary care offered through 14 pediatric subspecialty clinics at the Women's and Children's Health Centre of British Columbia. It is one of a very few programs that has a clinical pathway developed for health care providers. The pathway identifies transitional tasks that are emphasized along a developmental continuum from early to late adolescence. The acquisition of transition skills is documented and included in the health record along with a transition summary to ensure transfer of essential health information to adult health services.

Good2Go (Kaufman & Pinzon 2007) is the transition program developed at the Hospital for Sick Children in Toronto, Ontario. This is a centre-wide initiative that focuses on the alliance between the adolescent, family and health providers to shift the responsibility for health care decision making to the adolescent. Youth are taught specific transition skills and group programs are offered to youth and parents. A web-based personalized, portable health passport software program has been developed as part of Good2Go and has been adopted by many health facilities across Canada and the United States.

The On Trac and Good2Go programs have both been evaluated and assessed for their compliance with the recommendations articulated in the Canadian Pediatric Society (Canadian Pediatric Society 2007) and the Society of Adolescent Health and Medicine (Rosen et al 2003) position papers on the key elements for transition programs. Grant & Pan (2011) concurred that all recommended elements of an evidence-based transition program were identified in these two programs. Other transition programs available in Canada meet only a subset of the recommended elements.

The Be Your Own Boss program for adolescents with chronic conditions is the world's first official adaptation of the Stanford Chronic Disease Self-Management Program for adolescents (Alberta Health Services 2008). The six-week program is designed for teens and young adults with chronic conditions such as diabetes, multiple sclerosis, asthma and cancer who are moving from pediatric to adult health services. This program is led by young adults with chronic illnesses but does not involve parents in any way. In 2009, the Be Your Own Boss program was also initiated as a pilot project in Victoria, British Columbia and Winnipeg, Manitoba. The results of the evaluation of these pilot projects is not yet available.

The Maestro Project is a program that was launched by the Winnipeg Regional Health Authority in July 2002 (Van Walleghem et al 2006). The program uses a centralized, co-ordinated community-based navigation service for the care, education and support of diabetes for youths in Manitoba, Canada. Other service delivery strategies implemented by the program include a comprehensive website, bimonthly newsletter, a drop-in program and educational events.

Stinson et al (2008) have developed and evaluated a web-based self-management program for adolescents with arthritis in Ontario. The program has 12 modules for adolescents and two modules for parents. Early evaluation findings indicate that the internet will likely assume a major role in the delivery of self-management interventions for pediatric and adult patients with chronic health conditions. There is early evidence that internet-based self-administered interventions are efficacious for children with asthma, diabetes, headaches, cancer and eating disorders (Stinson et al 2008).

This overview of transition program in Canada is not intended to be exhaustive. Rather, it illustrates a broad range of intervention programs focused on adolescent transition in health care that to varying extents include elements known to facilitate positive transitions. As this is a growing area of inquiry, it is not surprising that a multitude of interventions have arisen. Each of these programs has unique features that are reflective of regional variation in health services and philosophy regarding best practice in transition.

In the same vein, the You're in Charge program is an early preparation for transition program. Based in Nova Scotia, one of Canada's Maritime provinces, You're in Charge began as a partnership between a health funder (the provincial Department of Health and Wellness), a pediatric health centre (IWK Health Centre) and an academic research group (Dalhousie University School of Occupational Therapy Chronic Condition Management Research Group). The next section of this paper details the evolution of the You're in Charge program.

You're in Charge – early preparation for transition/self-management for families with young adolescents with chronic illnesses

Phase One

In March 2009, the Nova Scotia Department of Health and Wellness, Primary Health Care Division approached the Chronic Disease Management Research Group based at the School of Occupational Therapy at Dalhousie University, and the Executive Director of Primary Health at the IWK Health Centre to conduct an environmental scan and scoping review related to chronic disease self-management services and supports for youth with chronic conditions in the province of Nova Scotia.

An extensive review of the transition literature was conducted. Interviews and focus groups were held with health charities, youth living with a chronic condition, and parents of youth living with a chronic condition. Health care providers from the following care teams within the IWK Health Centre were also interviewed – Asthma, Cardiac, Chronic Pain, Diabetes, Gastro-intestinal, Hematology, Immunology, Mental Health and Addictions, Neurology, Oncology, Rehabilitation, and Rheumatology. A questionnaire was circulated to staff in various District Health Authorities where the adult version of a chronic disease self-management program had recently been implemented. The results of this environmental scan highlighted the following issues:

- Chronic disease self-management is part of a transition process that can be conceptualized in stages, depending on the age and growth and development of the child/youth.
- Youth do not identify themselves by their chronic condition, and generally consider themselves to be 'normal' teenagers.
- Youth spoke highly of the 'camp experience' which gave them an opportunity to meet (face-to-face) other youth facing similar issues, create a social support network, have fun and learn about self-management outside of the clinical setting and in a manner which was not like a formal classroom/school.
- Parents have a need to learn skills/techniques to support the ongoing process of transitioning and enabling their children to independently manage their chronic condition.

Recommendations from the environmental scan and scoping review included:

- Develop and deliver a youth-focused, developmentally appropriate self-management program in a non-clinical setting applicable to youth with any chronic condition.
- Follow-up the weekend retreat/camp experience with online support, which would allow youth to remain connected to the social support network they established.
- Develop a program/approach that would provide parents with the opportunity to connect with one another and build on their ability to enable/empower their teens to begin to independently manage their chronic condition.

As a follow-up to Phase One, additional funding was provided by the Department of Health and Wellness in 2010 to develop and pilot a self-management workshop for youth and their parents in keeping with Phase One recommendations. A project coordinator was hired to oversee and manage the initiative.

Phase Two

Youth engagement in all aspects of program development and implementation was sought to ensure that the unique needs and strengths of youth were reflected in the workshop. A team of older youth (17 to 19 years of age) who lived with a chronic health condition were recruited and invited to participate in the development and implementation of the project. The content for the workshop was determined by an advisory committee comprised of clinical experts and academic researchers with knowledge and expertise in chronic disease self-management principles. The workshop was designed to be offered on a Friday night and Saturday format. The Friday night programming for youth was designed to achieve a 'camp' like atmosphere that would be carried over to the Saturday workshop. Through a partnership with Heartwood, a private not-for-profit youth development agency, a Youth Leaders Kit was developed and tested, and six youth leaders were trained to facilitate the workshop. Parents were engaged to determine focus areas for the parents' session. A recruitment plan was implemented and efforts were made to reach youth in a variety of settings and geographic areas.

The intervention for the youth launched with an evening at the Atlantic School of Circus Arts. Circus school provided an opportunity to model the concepts that were the focus of the workshop: watching others demonstrate a new skill, taking chances and trying new things, learning from others, and taking risks. Most importantly, circus school was fun, and the youth were able to start the Saturday session feeling more comfortable with each other.

On the Friday evening, while their teens were at Circus School, parents attended the two hour Parent Session. This provided parents with a chance to connect with other parents and explore their concerns, develop an action plan and set their own goal(s)? During the four weeks after the Parents' session, regular follow up and support was provided to families through a series of parent teleconferences. Each teleconference explored a topic area identified as important by the parents.

On Saturday the intervention continued with the You're in Charge! Workshop. Key topics were explored by youth leaders through one-on-one work, small group discussions, and through larger group discussion on:

- What the teens were in charge of at present and what they would like to be in charge of in the future.
- What they were doing and could be doing to keep themselves well and healthy.
- What has helped them be in charge and what were barriers for them to be in charge.
- How to set a personal goal that is specific, achievable and measurable.
- Create an action plan to achieve that goal over the following four weeks.

Over the course of the intervention, each teen received a Wellness Toolkit including a water bottle, lunch bag, T-shirt and a fully loaded USB stick. Teens developed an action plan around one or more goal(s) and learned about the follow-up support offered through the workshop. A highly interactive online support mechanism was needed to facilitate the engagement, learning, confidence building and peer support of highly digital, web savvy youth. After much discussion, a social networking site used at the IWK called Upopolis was chosen.

At the end of the sessions on Saturday, parents returned and both parents and teens shared the highlights of the youth workshop and parents' session with each other and shared their action plans; many were surprised to see that their individual action plans related to complementary goals.

Phase Two results

Due to the very small number of youth and parents who participated in the pilot version of the workshop only descriptive, qualitative data were collected. Youth participants gained confidence, and experienced success setting and achieving goals. They were supported by their parents to achieve this result. As a result, they were more involved in the management of their condition. Parents gained an increased awareness of the opportunity for negotiating youth independence behaviors. Parents perceived themselves to be more able to support their children's attempts to self-manage and perceived their children to be gaining self-management skills. Youth leaders experienced a variety of benefits as a result of their participation in the project, including a sense of accomplishment, and a desire to "do something more meaningful with my life." All of the youth and parents interviewed found the program beneficial and would recommend it to others.

The limited evaluation data did not deter the program funder from investing in a third phase of the project. The advisory committee considered the recommendations and developed additional materials for parents, as well as refined and revised the content of the youth program. The advisory committee closely examined the anticipated outcomes and activities of the program and recommended the inclusion of six standardized measures for the evaluation of the next phase of the program. These measures included:

1. Transition Readiness Assessment Questionnaire – Youth Version, v. 4.1, (Sawicki et al 2011).
2. The Partners in Health Scale (PIH) (Petkov et al 2010).
3. Child and Adolescent Social Support Scale (CASSS) (Malecki & Demaray 2000).
4. TRAQ Parental Version (Sawicki et al 2011).
5. Collaborative Parent Involvement Scale (CPI) (Nansel et a 2008).
6. Parents Helping for Health Inventory (Harris et al 2008).

Phase Three

As part of the work to make the program replicable across the province, a decision was made to run the program in a rural setting. One of the District Health Authorities in close proximity to the major urban centre where the IWK Health Centre was located was approached and agreed to host the program in a small community. The program was also repeated in the urban centre during Phase Three.

Two trained youth leaders were invited to return; one new youth leader was recruited to join the team. The Youth Leaders' Training was revised based on feedback from the youth leaders, staff at the IWK and the evaluation results. The training included expanded communication and facilitation skills, minute-by-minute review of the agenda for the workshop, and role playing; it was held over two days. Two masters level students from the School of Occupational Therapy worked closely with the leaders to develop the revised content and co-led the training sessions. The Youth Leaders Kit was revised to reflect the changes to the training and provide additional information and tools for the youth leaders.

It was recognized that there was a need to try Facebook, a social networking internet site, as a means of providing ongoing support to the teens involved in the program. A meeting was held with IWK Health Centre Public Relations Department, Privacy Committee and the Research Ethics Board to determine how to move this forward. A Privacy Impact Assessment (PIA) was completed and approved by the Privacy Committee, an educational tool on online safety was created, a request to create a Facebook account was granted by Public Relations, and a protocol developed to outline this approach. The PIA was approved, permission given to create the Facebook account, the ethics application was approved, and using Facebook was implemented.

Phase Three results

A total of 11 families participated in Phase Three of the program. Six families attended the session conducted in urban setting and five families participated in the rural session. A total of 11 youth, aged 12-16 years, (7 females and 4 males) and 14 parents (10 females and 4 males) were involved. Three of the youth had Type 1 Diabetes. The remaining youth all had different chronic health conditions including: asthma, Crohn's disease, celiac disease, brain tumour, aplastic anemia, spina bifida and epilepsy. One youth had a cecostomy, and three of the youth had multiple co-morbidities. Data collection proved to be a major challenge, particularly after program completion. Nine youth and four parents completed the post-program measures. Feedback from participants indicated there was a large burden to fill out forms for a short program.

Youth results

Knowledge Measure

The Knowledge Measure was specifically designed for the program to assess the level of knowledge about self-management principles. One participant showed no change (score was 4 at pre and post) but all others scores improved. The change score was not statistically significantly different (p = 0.09).

Transition Readiness

The Transition Readiness Assessment Questionnaire (TRAQ) (Sawicki et al 2011) was used to determine youth participants' perceptions about their readiness for transition and the assumption of self-management of their health condition. Change scores were examined by comparing the mean scores for each domain at pre- and post-program. A t-test was conducted to determine if the change scores were significantly different. On the self-management domain, the change score was not statistically significant (p = 0.334). The same result occurred for the change score for the self-advocacy domain (p = 0.798).

Ratings of self-management behaviours

Using a standardized measure, the Partners in Health Scale (Petkov et al 2010), youth participants rated their own self-management behaviours. Pre-program total scores on this 10 item, self-report scale ranged from 4 to 33 with a possible range of 0 to 80, where individual items were rated from 0 (excellent) to 8 (terrible). Most youth participants scored themselves poorly on their ability to make appointments for their health care independently. Following the program, youth participants' scores for items ranged from 17 to 27. The change scores were not statistically significantly different (p = 0.231). The post-program scores indicate the ability to share in decisions about the management of their health was rated most poorly. This may reflect an increased awareness of what it actually means to participate.

Parent results

Knowledge Measure

As with the youth participants, a knowledge measure was designed to assess the level of knowledge about self-management principles. Pre-program scores were available for all 11 parent participants while post-program scores were only available for four individual parent participants. All parental scores increased at post-program administration. These change scores were found to be statistically significant (p = 0.02). Despite the very small sample size and the dichotomous response scale, this result is promising.

Perceptions of Helping Behaviours

The Parents Helping for Health Inventory (Harris et al 2008) is a tool designed to estimate parental perceptions about how their youth and the health care system interpret their helping behaviours. Mean scores were calculated for each parent for the entire measure. At pre-program data collection, scores ranged from 1.64 to 3.80 with a mean of 2.62. Post-program scores ranged from 1.53 to 3.07. Lower scores indicate an improvement in parental perception of how their helping behaviour is interpreted.

Fostering Independence Measure

The Collaborative Parent Involvement Scale (CPIS) (Nansel et al 2008) was again used both pre- and post-program to measure parental perceptions of their readiness to foster independence and self-management of their youth. Pre-program scores ranged from 3.33 to 5.0. Post-program scores ranged from 3.56 to 4.78. There was no measurable change in these scores from pre- to post-program.

Qualitative Findings

Following their participation in You're in Charge, youth participants who completed the evaluations reported increased readiness and increased knowledge of self-management principles. These youth participants also rated their self-management behaviours more positively.

> *"I realized that I need to start doing more to get ready for when I move out."*
>
> *"I felt good learning about how to do many things for myself."*
>
> *"I learned the importance of knowing my health history."*
>
> *"I learned how to take control of my medication condition and cope with it, and my health."*

Youth reported reaching specific goals related to self management, such as speaking directly to their doctor, managing their medication.

> *"I've been going into my doctor's appointments alone for the 1st half and also started ordering my meds. My mom would do this all before the program and now I do it."*

Parents made observations about their teen's behavior as well:

> *"After the You're in Charge Program he ordered his prescription willingly at the drugstore."*
>
> *"One of the first things she wanted to do is become more responsible for taking her meds and planning for it. Instead of asking me to do it, she started calling in refills."*

Parents who took part in the program increased their level of knowledge about self-management principles as well.

> *"For me it's just letting go. As parents of kids with chronic illnesses, we are geared to organizing her medications, and keeping on top of their doctors' and specialist appointments. It's hard to let that responsibility go."*
>
> *"I learned to allow my child to take more responsibility."*

One mother reported changes in her daughter's ability to engage with her doctor, and just as importantly, her own ability to support her daughter in that.

> *"I think she's just a lot more aware now of what's going on … now she interacts more with her doctor. I also stand back."*

Parents were found to consistently rate their child's readiness as higher than the child rated themselves. There was an improvement in parental perception of how their helping behaviour is interpreted by their youth.

> *"What I learned … the importance of having a transition period as my daughter takes on more responsibility for her health."*

One teen reported taking on more aspects of her own care, the impact this has on her, and on her relationship with her mother.

> *"I've been able to do some things on my own. It makes me feel like she (mom) is letting me get older and I can start doing things on my own."*

Overall, parents reported feeling more positive and hopeful about the future and more confident in their ability to negotiate the transition with their teen.

> *"I feel positive that we can accomplish our goals."*
>
> *"The program has helped us get on the right path."*
>
> *"She is growing up and I want her to be ready for her life."*
>
> *"I don't have to be 100% responsible for her health. She can do most of it herself."*

Conclusion

This paper describes the positive impact of a developing early preparation program for transition and self-management for families with adolescents with chronic illness. To date the low numbers of participants has hampered the collection of quantitative data to support the effectiveness of the program. The qualitative data indicate that youth and parents find the program beneficial. The You're in Charge program has been designed to incorporate the features of transition programs that have been examined empirically. It is proposed that families with adolescents between the ages of 13-15, who have a chronic illness be invited to participate in this program as a first exposure to the issues around transition. Youth and their families will need additional exposures to programs and services that will continue to support their preparation for the move to adult health care services.

Further empirical work is needed to confirm the efficacy of this program. Issues of recruitment, evaluation burden, and sustainability continue to require attention. Succession planning for the youth leaders is another area to be addressed. Exploration of partnering with a newly built residential camp for children and youth with chronic illness in the province is planned for Phase Four. Finally, as with other transition programs across Canada, occupational therapists have been integral to the design and implementation of the You're in Charge program. Phase Four will include collaborative work between the researchers and graduate students in occupational therapy to clearly articulate the relationships between transition, chronic illness, youth engagement and occupation.

The unique contribution of the occupational therapy lens on the person-environment-occupation interaction adds depth to the interventions for transition. Occupational therapists have the capacity to view the complexity of transition in ways that education, psychological or behavioural approaches alone cannot. Transition to adulthood for youth with chronic illness or childhood onset disabilities is not confined to their interaction with the health care system. This transition has an impact on employment, education, independent living and contributing to the social fabric of the community where youth live. Occupational therapists are and must continue to be leaders in best practice in this area.

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Significance of culture when working with clients and their families





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Abstract: *Culture often has a strong impact when families accompany clients or are part of the intervention experience. The dominant culture of the society may not be representative of the specific family culture, particularly with regard to specific ethnic groups in their original locale or as immigrants in another region. The purpose of this article is to emphasize the significance of culture and the recognition that geography alone does not necessarily pinpoint cultural variations. Varied situations when dealing with families of different cultures are demonstrated through specific examples of nuances related to cultures within cultures, including gender issues, age differences, deference to particular family members, expected behavior in a client's home, and occupations that imply status and recognition within certain contexts. Areas of diverse cultures may be found in many countries. They need to be respected and considered when determining intervention goals. Examples of educational approaches to prepare students for dealing with familial variations within the cultural environment are discussed.*

Key words: Culture, empathy, ethnic customs.

Introduction

Occupational therapy takes a holistic view of the individual and the family. Client centered therapeutic goals are not isolated; they incorporate interactive factors. One of these significant factors is culture. Yet culture needs to be viewed in context and could be subject to change. Although migration may lead to cultural variations, even within the primary culture there are unique groups. Culture may impact on therapeutic goals and the methods used to accomplish them. Cultural implications may become more evident when working with families, as different from working only with individual clients. Wray and Mortenson (2011), using ethnographic models, found that cultural themes occurred within the context of "family-centered partnerships" (p. 180). The significance of culture may be more apparent with generational issues particularly in relation to parent-child or grandparent-child relationships, environmental issues as in home based therapy or evaluations, and with regard to specific areas of activities of daily living (dressing and eating styles). Patterns of parenting and who might be allowed to assist in child rearing or caring for disabled family members include cultural expectations related to gender roles, authoritative designations, and more.

Some of the questions and areas to consider when planning a first visit to a client's home or encountering a family member in a clinic are:

- To use culture practices advantageously in practice, what should an occupational therapy practitioner try to find out before meeting a family?
- Does it matter whether the occupational therapy practitioner is male or female?
- What clothing is acceptable?
- Who has responsibility for family decisions?
- What are the expectations regarding intergenerational communication?
- Are there items within the home that should not be touched?
- Are there particular greetings that would be more meaningful?
- Are there restrictions to the use of hands in eating or gestures?

- What should the therapist do or not do to practice culturally sensitive family centered care?
- Is there something that should not be brought into the home or introduced in treatment that could be contrary to the practices of the particular culture?

Considering such questions in advance better prepares the therapist for unanticipated cultural encounters. Although culture is generally identified as a way of life of a people and includes beliefs, art, customs, language and religion acquired by a member of a society, "...there is at least as much diversity within groups as between groups" (Sherif-Trask 2007, p. 132).

Cultural issues affecting client services

Within a country of immigrants, such as the United States of America, or even a city like New York City, there are pockets of micro-cultures (Neuliep 2009), sometimes considered minorities, that tend to expand as extended family members and friends choose to live in the same vicinity as others who speak the same language, purchase similar foods and clothing, and share the same customs. Often larger cities will have regions such as a Little Italy, Chinatown, Little India and neighborhoods that are known to have concentrations of particular ethnic groups with restaurants, places of worship and stores that cater to their needs. While newcomers may move toward acculturation within the dominant culture, this could alienate family members who want to retain the values and customs of the "old country." Major areas of cultural conflict include respect for elders and maintaining family rituals, particularly those related to traditional gender roles, family hours and social mingling.

Both Dickie (2004) and Darnell (2002) address the cultural impact on human occupations. They note that while preparing a client for discharge to the community, mobility as well as actual cultural role expectations within the family need to be addressed. The picture may be dramatically different in varied cultures. Parenting roles, educational roles, gender roles and occupational roles (expected tasks) can be quite varied even in different parts of the same country or between rural and urban areas in various regions, where shopping could mean walking to the nearest store with a credit card or bartering at a street market stall. Family patterns, intergenerational expectations and gender roles provide examples of some of the issues that must be considered in relation to cultural awareness.

Family patterns

Family patterns have carried over to immigrant cultures, which also show differences in religious customs, types and styles of food, dressing, communication styles and language, values and social expectations. For example, although eating is a family-oriented affair in many cultures, siblings from Ghana in village life eat with their hands from the same shared bowl on the ground while parents eat separately. Children are expected to greet their elders in the morning, showing respect by specifically identifying each, "Good morning, Mommy," (Bueno et al 2011).

Family and regional patterns of clothing and food, common practices, language and beliefs also vary from by geographical area. Awareness of the family patterns is important. For instance, dressing styles amongst women in India include Salwar Kamiz, the widely used dress by North Indian women, while women in the South wear saris. In addition to the pleating and draping style over the shoulder, one of the observable differences among saris in different regions of the country is the fabric itself. It may be woven, dyed or embroidered with specific motifs and decorations (Nieuwenhuis 2009). In East India the Baluchari sari has a floral border design along the edge. Women in the west prefer saris with yet another twist of the fabric when tucked in. There is a similarity in expectations in various parts of Pakistan related to women's wearing apparel; women may cover their whole bodies and may consider that it provides a sense of security to them. A very different culture, that of orthodox Jewish women, follows similar practices with long skirts, sleeves and head coverings. Middle Eastern women may wear a large square scarf, a band to keep it from slipping and a manner of attaching it toward one shoulder. Therefore, dressing assessment and dressing training may vary even within an assumed culture. Adaptations may need to be considered that allow for these cultural variations.

Regional practices and beliefs vary. Mettapalli, Mukerji, and Mukerji observed through their early intervention practice that when working with families from India, the right hand is reserved for eating, holding and drinking water at the table and the left hand is dedicated to taking care of bathroom functions (personal communication, November 12, 2012). This knowledge is necessary when doing assessment and training, particularly with people who have had a stroke.

Awareness of accepted cooking and eating habits is imperative when working with people of different cultures. For instance, in a Hindu household, as cows are considered holy, beef is not a food option and a family may choose to be vegetarian. In a Muslim household, pork may not be eaten under Islamic belief and meat needs to be Halal. Also, in Jewish culture, pork is not eaten, food has to be kosher, and dairy and meat products are kept separate. Vegetarians do not eat meat, poultry, fish or seafood. Vegans do not eat animal products or animal by-products.

Using appropriate forms of addressing individuals will support communication and respect. There may be language preferences at home, and forms of address may involve choices related to use of first or “private” name versus family or last name. For instance, individuals from Caribbean cultures, such as Jamaica, may prefer the use of the title and last name. Martin and Chaney (2012) discuss differences in greeting men and women, particularly in countries where women retain their maiden name or add their father-in-law’s or where one should wait to see whether a woman extends her hand for a handshake.

Disability may be perceived differently by people in different cultural groups. In some cultures the therapist may need to enlist a family member to encourage the client to cooperate as sickness or disease may be thought of as a punishment that needs to be accepted and endured but not necessarily cured or remediated. Immigrants may be misunderstood in their new adopted country regarding concerns over clients’ behaviors. In many Asian cultures family members are expected to look after individuals who are disabled and do not necessarily expect those with disabilities to try to be as independent as possible. They are expected to be passive and not active participants in their rehabilitation. With the influx of immigrants from Latin America, hospitals in Miami, Florida had hired anthropologists to help differentiate ethnic customs and rituals from psychiatric behavior. Similarly, Pooremamali et al (2011) consider mental health issues when emphasizing that, “Recent waves of global migration have generated a new mix of people with greater differences in cultural assumptions” (p. 109).

Intergenerational expectations

Parent-child links may differ based on gender expectations and occupational roles for the particular cultural group. The bond between grandparents and grandchildren in China is so strong that it is evident in ordinary street encounters (Chen and Liu 2012). Therapists can look at the advantage of this influential and rich resource. Considerations for the therapist include whether communication regarding a pediatric client should include the older generation caretaker or the parental guardian. At the other end of the spectrum are questions of discharge planning for an older adult who may be returning to a three generation household. Grandparents or extended family members may look after young children while the parents work, and in some cultures there is the expectation that children are expected to look after their parents in their old age. Arber and Timonen (2012) include findings from a number of countries on “shared cultural understandings” (p. 140), e.g. the impact of a welfare state on income and care in an aging Scandinavian society and the influential role of grandparents. Another example of policy impacting roles is the increasing number of grandparents designated as legal custodians as found in the United States, because the parents have difficulties in handling the parenting role. There are similar challenges for grandparents in Sub-Saharan Africa where HIV/AIDS has taken away a generation leaving grandmothers to take care of youth.

Gender role expectations

In many cultures there are separate roles for men and women. Social and behavioral norms for each gender are adopted, accepted or demanded. Gender role expectations may impact on people’s daily occupational performance. This can range in self-care from shaving a beard or legs to housekeeping or childcare responsibilities. In leisure activities there may be a greater male presence in active sports while in productivity more males are found working in construction and more females in teaching. Even within a family during daily occupational performance, such as serving meals, husbands and wives may not touch during a particular time of the month or in public. Gender role expectations also transfer to the clinical encounter. Depending on the region the family is from in India, Pakistan or the Middle East, as an example, if a male member of the family is not present in a one-on-one situation, it may be unacceptable for a male occupational therapists to provide treatment. Personal touch can include subtle nuances; the transferring of an object from the hand of one person to that of another may encounter forbidden touch.

Another example could be as simple as a retro massage of the fingers or even assisting in transfer from bed to wheelchair.

In a number of cultures there are daily occupations that are traditionally considered male or female. In observant Muslim countries, for example, women are not allowed to drive cars. Also, some types of work are usually viewed as being more suitable for men or women. Nursing is heavily dominated by women. Some leisure type occupations are gender stereotyped; for example, few men knit or sew while few women play football or horseback polo. More girls play with dolls and more boys play with toy trucks and cars. Yet, intermingling of cultures has led to, perhaps, surprising blending or shifts as practices have been absorbed by new groups. Thus the same mahjong that had been played outdoors by Chinese males is now a favorite table game of Jewish women vacationing in mountain resorts.

Applications

A number of potential issues were mentioned above, ranging from variations in the handling of activities of daily living categories to perceptions of disability. As an example, in many devout Muslim countries, women can only interact with other men if they are their father, brother, husband or other designated male family member. However, it serves us well as therapists to focus on similarities and choose to be aware of how to handle needs that particularly impact on specific therapeutic goals. An additional setting where therapists can apply their cultural awareness to client or family centered service includes family wellness programs or after-school clubs.

In the home environment

The perspective of culture is often more apparent in the home context since not only language, customs, and family ritual, but also the décor reflects cultural practices and values. Mallari shared information contrasting immigrant families in her home care practice (personal communication December 13, 2012). She found that those from Poland and other Eastern European countries were more likely to allow the client to choose not to participate in therapeutic activities, while those from Latin America were more likely to urge involvement in therapeutic exercise at home.

There has to be a clear demarcation of safety versus cultural style. Homes filled with knickknacks and piles of old newspapers may raise questions for an therapist about whether to implement a de-clutter program or alternatively consider this to be part of the cultural landscape. Therefore, the rationale for a de-clutter program might need to relate to specific goals, such as safety for an older person living alone, and this needs to be clearly discussed and negotiated with the client and the family members. Where it becomes a potential hazard interfering with wheelchair mobility, for example, the therapist may choose to speak with family members in a sensitive manner and offer assistance to modify the environment. Therapists may need to ask before moving an item in the home as the action could trigger apprehension because something was handled by a person inappropriately.

Therapists need to be sensitive to cultural habits that may require knowing when to intervene and when not to intervene in a home context. There are ethical issues that may need to be evaluated from a cultural point of view as the therapist attempts to build cultural bridges in working with the family in a home situation. If a client's safety is at risk or if a client appears to be in an abusive situation, after the cultural issues have been taken into consideration, therapists still have a legal, moral and professional responsibility to not leave clients in an unsafe or dangerous situation. If therapists do this, then they are at risk for professional censure and legal charges.

In the rehabilitation setting

Organizational structure and policies may impact the role of family in the rehabilitation setting. Family members are sometimes discouraged from being present during therapy sessions because of limited space or sensitivity to the privacy of others. However, appointments may be specifically scheduled to orient family members to post-discharge needs. In some in-patient clinical settings family rooms are designated for private conversations and even hugging to provide for a family's particular needs.

When working in early intervention there is a need to involve a family member who can carry over treatment. Language factors can include not only local language nuance which the family member is familiar with, but also tone and volume. Even gestures can have changeable meanings within the cultural context. Gestures can highlight emotion and the intensity of a situation.

Wells (2005) defines cultural competence and gives specific examples such as being cautious during touching (as noted above), conducting the session in the preferred language, involving the extended family in the intervention process and adding culturally related questions during the evaluation process. The University of North Dakota's *Occupational Therapy Cultural Competency Resource Guide* (2010) enables the reader to specifically click onto resources online related to eleven identified cultures. The site also encourages the reader to try to take on another person's perspective as a way to become culturally competent. That may also be considered one of the principles of a successful outlook in relation to family life.

Educational Initiatives for cultural competency

As curricula prepare occupational therapy students for cultural competency in communities with increasing diversity, there are a number of effective educational techniques that can enhance the process. Scheer (2008) provides specific principles for testing and verifying the achievement of cultural competency through education. Occupational therapy educational programs located in a multicultural environment provide their own microcosm of varied contexts within the culture of the organization. There may be direct instances of family units among the students: father-daughter, aunt and niece, siblings, and other combinations. Thus the college community can allow for cultural awareness of families through encounters and sharing information about each other's cultural patterns. Educational approaches that may be used to promote global cultural immersion and better enable students to apply principles in their practice settings include international fieldwork, in-class cultural presentations, empathy narratives, and cultural diversity booklets.

International fieldwork

Hayward and Charrette (2012) state, "Curricular models that provide meaningful connections between the classroom and the real world are important for cultural competence…" (p. 78). Even short term international experiences can enhance awareness of family styles within specific cultures. During an occupational therapy mission in Jinotepe, Nicaragua, (Greenberg 2006a) family mobility included older siblings pulling barefoot special needs children to school in wooden wagons. This was part of rural family life where clothes were washed on scrubbing boards in sinks where the water flowed directly to the ground without a drainpipe.

Burggaaf and Bourke-Taylor (2008) described a cross cultural exchange in the Solomon Islands where fieldwork observations included, "large extended families living in western style houses, tin shacks or picturesque huts on poles" (p. 190). This reinforces the concept of different cultural patterns in the same country. Encouraging international fieldwork, the American Occupational Therapy Association adopted ethical guidelines for such experiences (Crist et al 2011). Total immersion assures recognition of the actual experiences and values of a very different familial environment. For example, a student from Granada chose occupational therapy fieldwork in Israel because of her prior experiences as a home health aide. She stayed with a family where she learned first-hand about informal social interactions, elaborate cheese and vegetable breakfasts and more. She then carried over her positive feelings to her work in a psychiatric hospital at which she also met with family members of clients.

Cultural presentations

In an urban multicultural environment in the United States an assignment prompt in an occupational therapy educational program directs students to share family experiences from a cultural perspective in a show-and-tell type presentation. Some students choose to highlight clothing, family crafts, and food preparation. Differences range from pre-cutting food in the kitchen and serving it in family plates at the center of the table to be eaten with chopsticks (Hong Kong) to use of knives and forks and individual servings in Western style. While Chiang and Carlson (2003) consider both immigrant cultural groups and indigenous cultural groups, they concentrate on Western cultures in their discussion on the implications for occupational therapy education of culturally competent practice. A standard cultural classroom presentation to peers could be upgraded by having each student introduce a scholarly article to support an element of the presentation.

Empathy narratives

Martin (2008) focused on clients and therapists who were of different ethnic backgrounds than each other and among other topics, examined the empathetic relationship between them. In an empathy building exercise in which the authors were involved, each student was assigned a randomly selected patient's diagnosis. Students created biweekly first person scenarios describing their fictional character from age 3 months through to age 70. All of the stories started with family life and feelings. Most of the stories continued to include the family in the evolving picture. The feedback clearly showed varied family perspectives from abandonment to support, from identity to rebellion. The students were from diverse cultures and incorporated elements of those experiences into their narratives. Brown et al (2010) make the recommendation that investigation should be made of occupational therapists' empathy levels when working with different client groups. Cultural categories can be the way to differentiate such client groups.

Cultural diversity booklets

Compilation of cultural diversity booklets and web collections used in teaching and learning sessions covered such interrelated family topics as values, cooking, aging, activities, death and more (Greenberg 2006b). Most of the entries focused on concrete visible examples of contrasts in cultures. The *Cultural Diversity in Cooking* booklet featured a separate page per recipe and included reflections about therapeutic aspects of preparing the dish, including family participation and associated occasions. *Cultural Diversity in Values* examined in individually authored paragraphs, less tangible family issues including curfews and parental approvals (recent South American and Asian immigrants) in contrast to local city dwellers asserting independent decisions. Some participants alternatively considered idiomatic language and gestures with one contrasting the seriousness, preciseness and structure of German culture with that of a joking Irish experience.

Discussion and conclusion

While the authors addressed culture in the traditional ethnic geographical sense, they recognize the importance of context as in Iwama's (2007) broadened definition of culture, "shared spheres of experience and the ascription of meaning to objects and phenomena in the world" (p. 184). The occupational therapy practitioner can draw on the rich resource of culture, harnessing its strengths. By integrating cultural family experiences in the home, school and the community the therapist can find innovative ways to enhance occupational performance. The World Federation of Occupational Therapists recognized the importance of cultural awareness with its *Guiding Principles on Diversity and Culture* (2009). Since its publication, the literature shows increasing studies of particular cultures in their original locations and a focus on accommodating immigrant cultures. Sensitizing potential occupational therapy practitioners through educational experiences better enables them to recognize, in their areas of practice, hidden cultural opportunities among families. Practitioners need to recognize that clusters of ethnic family groups may not be representative of the dominant culture. Being aware of this possibility may ease the transition into a positive therapeutic relationship. While actual family encounters may be most effective in developing awareness of specific ethnic customs and differences, educational initiatives can help to promote empathy and sensitize future occupational therapy practitioners toward recognizing and respecting values of others that may be different than their own.

As clinicians it is our duty to acknowledge and embrace the differences. This will enable us to work with families with a better understanding of the factors that will ensure the highest results and efficacy. Both clinicians and administrators need to be aware of the existence and interrelationships of various sub-cultures within the larger culture, and that various familial relationships that emerge from cultural interactions can have both positive and negative impacts on overall therapeutic goals.

It may be useful to ask some questions of how to further the understanding of culture. Such questions might include: Does having a therapist from the same ethnic group for family therapy make an actual difference in outcomes? Is there an advantage to acknowledging cultural family norms over justifying the need for accommodating variations? Can building on recognized family cultural strengths enhance compliance with intervention and expedite results? Are students who participate in a first person narrative, based on a randomly selected diagnosis, at intervals from birth through adulthood more likely to appreciate the impact of culture on family therapy? It would also be useful to refer to the *WFOT Guidelines on Diversity and Culture* (2009) for further reflective questions to focus discussion among students and occupational therapy association members on the subject.

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Thera-Free: ten years of providing free and quality occupational therapy services to the underserved

Abstract: *In many countries, occupational therapy services remain inaccessible and inequitably distributed. This results in entire communities and populations not being served. A possible solution to the problem is the program* Thera-Free *conceptualized in the Philippines. This article describes the program and how it has been used to address the shortage of occupational therapists in the country. A case study details how the program was implemented in an island province and the challenges the program has and continues to face. It describes the initiatives of two occupational therapists who worked with a private group of women and the community to bring* Thera-Free *to the island-province. Finally, strategies to move the program forward are offered.*

R. Lyle Duque (Philippines)

Background

Many Filipinos with disabilities (and those who are at risk) are not able to receive occupational therapy services. Some of the reasons for this include the lack of qualified occupational therapists to serve the nation primarily due to 'brain drain' (occupational therapists leaving to work in other countries); inequitable distribution of occupational therapists across the country; and non-inclusion of occupational therapy services in the national health insurance system (Bondoc 2005, Duque and de Leon 2006). This predicament is not unique to the Philippines. Several countries, particularly developing ones, have to contend with a growing, but unfulfilled need for occupational therapists (Zhou 2006, Lim and Duque 2011, World Federation of Occupational Therapists 2012).

As a response to this need, the alumni of the College of Allied Medical Professions at the University of the Philippines Manila initiated a project called *Thera-Free: Libreng Therapy para sa Pilipino (Thera-Free: Free Therapy for the Filipino)* in 2002. The group was composed of occupational therapists, physical therapists, and speech-language pathologists. The objectives of the project are to provide free, accessible, and quality occupational therapy, physical therapy and speech-language pathology services to indigenous Filipinos; increase public awareness of the benefits of therapy; enhance social awareness and sense of social responsibility in Filipino therapists; establish networks and linkages between therapists and other health professionals and organizations; and provide a venue for research (Lim and Duque 2011).

The project is anchored on cultural knowledge and sensitivity, volunteerism and social responsibility, and collaborative practice (Duque and de Leon 2006). Communities that need therapy services are identified by the alumni or are referred to the *Thera-Free* program. The volunteers conduct an informal needs assessment to gather information regarding the community's culture, needs, resources and socio-economic condition. Volunteers then prepare home programs, education and training materials and coordinate with local community leaders in identifying those who need therapy services. Members of the community, the local government, or in some cases, private individuals and organizations, provide logistical support to the volunteers (Lim and Duque 2011).

Ten years into the program, *Thera-Free* has been conducted more than 60 times in more than 16 provinces around the country. Despite this, many areas in the country have yet to receive occupational therapy or any form of therapy for that matter.

Sustaining *Thera-Free* in an island province: a case study

An island south of the Philippine National Capital Region has only one registered occupational therapist. She is barely able to take in all the clients referred to her. She primarily works with children with disabilities. Occupational therapists and specialist doctors visit the island, but many persons with disabilities are not able to afford these professionals' fees, even if the fees are significantly reduced.

A female occupational therapist from the National Capital Region was contacted by a group of women-friends who wanted to conduct a free therapy project in the island. Two of them were mothers with a child with disability. The occupational therapist negotiated an agreement with the group of women. The agreement was related to the group providing transportation, food and accommodation for the occupational therapist; the group identifying communities that can be served in the 2-3 days that the program was going to run; the occupational therapist providing free services to the individuals identified including formulation of home programs that can be implemented by the client's family and other professionals working with the client (when applicable); and the group committing themselves to conducting the *Thera-Free* project every six months. The last provision in the agreement was vital in ensuring continuity and sustainability of the program.

The occupational therapist as clinician-volunteer, trainer, advocate and program consultant

During her first visit, the occupational therapist served two communities (one was a center for indigenous children and adolescents led by a religious group and the other a special school in an urban poor village at the outskirts of the city). All of the clients referred to her were children. She also conducted a short seminar for the parents of the children with special needs. However, she realized that there were more children who needed occupational therapy services.

She spoke with the group and requested that another occupational therapist be flown in during the next *Thera-Free*. The group agreed and a male occupational therapist was invited to join the subsequent *Thera-Free* projects in the island. Together, the two occupational therapists were able to serve more children and another community was visited (a public special school). They also conducted informal training programs for the family members, staff of the communities they visited, and the teachers in the schools. They have made recommendations related to the thrust and structure of the programs in the communities they visited so as to help these communities optimize their limited resources.

Additionally, the occupational therapists tapped their personal connections in order to acquire materials (for therapy, education and training) for the communities. They visit these communities every six months and continually monitor the progress of the clients and their families.

Challenges remain

Despite the work that has been done with the communities in the island, many more challenges remain. There is a need for more volunteers to provide occupational therapy to the island and at a more frequent rate. Persons from other age groups and communities who may benefit from occupational therapy need to be identified. Capacity building is of paramount importance in order to empower the members of the communities. To ensure the continuity of the program, it would be helpful for the occupational therapists to make representations with the local government unit and propose *Thera-Free* as a component of the local health program.

Conclusion

Thera-Free holds a lot of promise in addressing the need for accessible, equitable and quality occupational therapy services in many parts of the world. It is anchored on the humanistic underpinnings of the profession and the sense of volunteerism and social responsibility of practitioners. It requires occupational therapists to go beyond waiting for clients to seek their services, and work with the community in identifying persons or groups of persons who may benefit from occupational therapy.

After a decade of *Thera-Free*, many of the challenges it faced during its inception remain. It is an indication that the myriad issues affecting the program have yet to be addressed. It reminds us that occupational therapy, like all other health professions, exists within social, political, economic and cultural spheres that impact the profession's ability to fulfill its responsibility to serve society.

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Taller de sexualidad en pacientes con patología neurológica adquirida

Workshop on sexuality in patients with acquired neurological pathology

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Resumen: *El objetivo de este trabajo es compartir la experiencia de un taller de sexualidad incorporado como parte del tratamiento integral de pacientes en el proceso de rehabilitación psicofísica en el Hospital de Rehabilitación "Manuel Rocca" Ciudad Autónoma de Buenos Aires, Argentina.*

Es frecuente que los pacientes encuentren en las sesiones de Terapia ocupacional (T.O.), un ambiente propicio para expresar sus dudas, miedos y problemáticas acerca de su sexualidad y la sexualidad en pareja. La sexualidad es un impulso vital, esencial para el desarrollo y ajuste de la personalidad y un importante medio de comunicación interpersonal que debe ser tratado mediante una herramienta útil y adecuada.

Fue por ello, que elegimos abordar esta temática a través de la modalidad de taller dirigido por un equipo interdisciplinario, conformado por pacientes sin distinción de sexo ni diagnóstico, que manifestaran interés de participar voluntariamente. El objetivo fue el de brindar asesoramiento, esclarecer dudas y fomentar el uso de nuevas estrategias para el desempeño y expresión sexual.

Palabras clave: Sexualidad, rehabilitación psicofísica, discapacidad motora, actividades de la vida diaria.

Abstract: *The aim of this paper is to share the experience of a sexuality workshop incorporated as part of the comprehensive treatment of patients undergoing psychophysical rehabilitation at "Manuel Rocca" Rehabilitation Hospital in the city of Buenos Aires, Argentina.*

Often patients find in occupational therapy sessions an environment to express their doubts, fears and issues about their own sexuality and sexuality in couples. Sexuality is a vital force, essential for development and adjustment of the personality, as well as an important means of interpersonal communication which must be approached with a useful and adequate tool.

We chose to tackle this issue through the form of a workshop coordinated by an interdisciplinary team. The group of participants consists of patients, regardless of gender or diagnosis, who showed interest to participate voluntarily. The aim is to provide advice, clarify doubts and encourage the use of new strategies for performance and sexual expression.

Key words: Daily life activities, sexuality, psychophysical rehabilitation, motor disabilities.

Introducción

La sexualidad es un impulso vital, esencial para el desarrollo y ajuste de la personalidad y un importante medio de comunicación interpersonal. La sexualidad es abarcativa, es dinámica, se aprende, se construye a lo largo de toda la vida, no es equivalente a la genitalidad, ésta es uno más de sus componentes, junto al impulso sexual, la comunicación, los sentimientos, la comprensión, la ternura, el cariño y los contactos corporales extragenitales; es decir todo aquello referido al placer sexual. El ejercicio de la sexualidad tiene tres objetivos fundamentales: la gratificación individual, la gratificación de la pareja y la conservación de la especie.

La salud sexual implica una expresión integral, involucra aspectos biológicos, psicoafectivos y socioculturales equilibrados para el logro del placer; lo contrario puede originar una disfunción sexual (Posse F, 1991). Los órganos sexuales son aquellos que funcionan fundamentalmente cuando ejercemos nuestra sexualidad. Cada milímetro de nuestro cuerpo tiene la posibilidad de ser receptor de sensaciones placenteras siempre y cuando estén inscriptas a nivel cerebral como erógenas, y se haya producido un aprendizaje por medio de la autoexploración. Es importante reconocer que todas las zonas del cuerpo, aun no siendo tradicionalmente erógenas, son factibles de sensibilizarse por medio de un aprendizaje apropiado.

Se denomina personas con discapacidad físico-motora a aquellas que presentan alguna deficiencia (sobre una función o estructura corporal) que les dificulta o imposibilita realizar de la forma habitual, las diferentes actividades cotidianas. La Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud -CIF- OMS, 2001 utiliza el término "Discapacidad" para denominar a un fenómeno multidimensional, resultado de la interacción de las personas con su entorno físico y social.

Una discapacidad adquirida en la vida adulta ocasiona una crisis vital que abarca al sujeto y al medio ambiente donde se desenvuelve. Los cambios más importantes que la persona debe enfrentar son: el cuerpo sano perdido, el rol perdido dentro de la dinámica familiar y social (alteración de actividades cotidianas y laborales), el aumento de la dependencia y la pérdida de intimidad que implica la inclusión de un equipo de salud en la rutina de su vida cotidiana. En algunos casos, además del cambio en la imagen corporal se debe elaborar la incorporación de elementos y ayudas técnicas como ortesis, férulas, bastones, sillas de ruedas, etc. Esta situación provoca una crisis de identidad y una serie de duelos que la persona deberá resolver a medida que se adecúa a la nueva realidad.

El Marco de Trabajo para la Práctica de T.O. (AOTA, 2010), fue desarrollado para articular la contribución de la Terapia Ocupacional en la promoción de la salud y la participación de las personas hacia un compromiso con la ocupación. El apoyar la salud y la participación en la vida a través del compromiso con la ocupación, describe el alcance de Terapia Ocupacional en su máximo sentido, establece "una relación positiva entre la ocupación y la salud", basada en el conocimiento de que comprometerse con las ocupaciones organiza la vida diaria y contribuye a la salud y el bienestar.

Los distintos tipos de ocupaciones se ordenan en categorías llamadas Áreas de Ocupación, una de ellas son las Actividades de la Vida Diaria descriptas como: "Actividades que están orientadas al cuidado del propio cuerpo, son fundamentales para vivir en un mundo social, permiten la supervivencia y el bienestar". Dentro de esta categoría se encuentra la Actividad Sexual entendida como la "participación en actividades que busquen el placer sexual" (Christiansen y Hammecker, 2001).

Una de las áreas de intervención de la Terapia Ocupacional son las Actividades de la Vida Diaria. La actividad sexual forma parte de esta categoría y su desempeño es entendido como la participación en actividades que busquen la satisfacción sexual. La T.O forma parte del equipo de Rehabilitación y su contribución es la aplicación de valores centrales, conocimientos y habilidades para ayudar a las personas a comprometerse con las actividades diarias u ocupaciones que ellos quieren y necesitan hacer, de forma que contribuyan a la salud y la participación social. El compromiso con la ocupación, como el foco de intervención de la T.O, incluye el aspecto tanto subjetivo (emocional y psicológico) como objetivo (físicamente observable) de los aspectos del desempeño.

Es de suma importancia como profesionales de salud en el ámbito de la rehabilitación promover la adaptación de las personas a su nueva realidad, ayudando a su comprensión y promoviendo el desarrollo de actitudes activas y la búsqueda de alternativas favorecedoras frente a la situación actual.

Partiendo del hecho de que todos somos seres sexuados y de que no existe un modelo único de sexualidad, la intervención de T.O se orienta a favorecer el descubrimiento y la exploración de las capacidades propias de cada individuo y a promover un reajuste sexual adaptado a los propios deseos, preferencias y posibilidades reales.

Los estudios realizados hasta la fecha sobre este tipo de abordaje son bastante escasos y en la Argentina no se conoce ninguno.

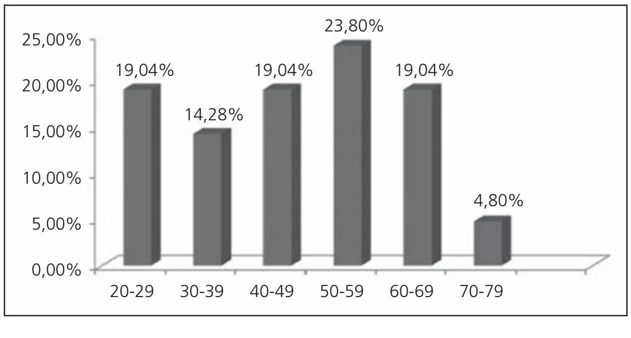
El fin del presente trabajo es compartir la experiencia de la implementación de un "taller de sexualidad" que permitió trabajar los aspectos relacionados con el esquema corporal, aceptación del mismo, su relación con los otros y su expresión sexual. El objetivo que nos planteamos es demostrar su importancia dentro del contexto de la rehabilitación.

Pacientes y método

Efectuamos un taller para abordar la sexualidad. Para ello, en la fase inicial se confeccionó una encuesta anónima y autoadministrada que fue suministrada a personas que estaban en tratamiento y asistían a T.O. Esta encuesta permitió obtener datos de la población en cuanto a su conocimiento del tema, su interés en participar y las preferencias de modalidad de abordaje.

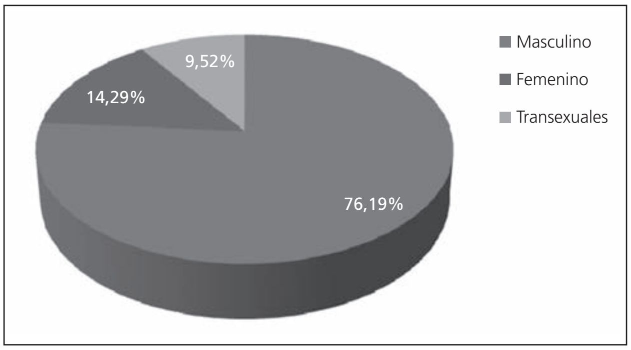
Resultados de encuesta inicial

Edades

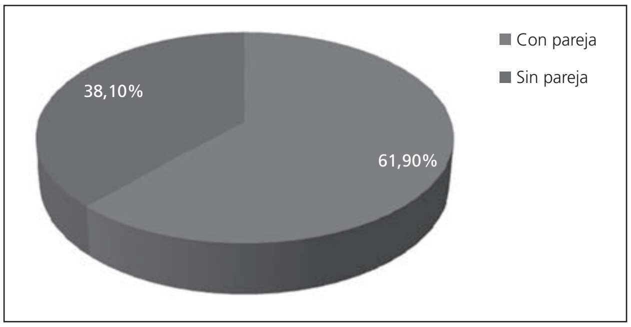


Los criterios de inclusión aplicados fueron: personas que se encuentren en tratamiento en el Hospital de Rehabilitación Manuel Rocca, mayores de 18 años, que presenten interés en participar voluntariamente del taller.

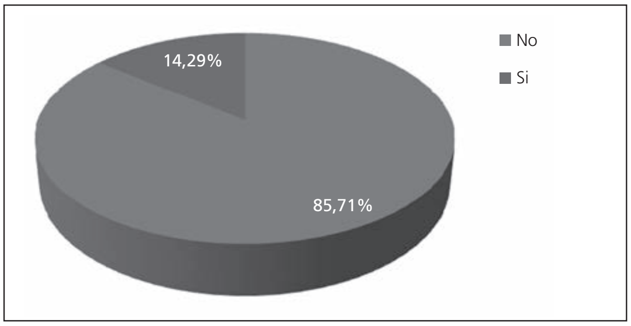
Géneros



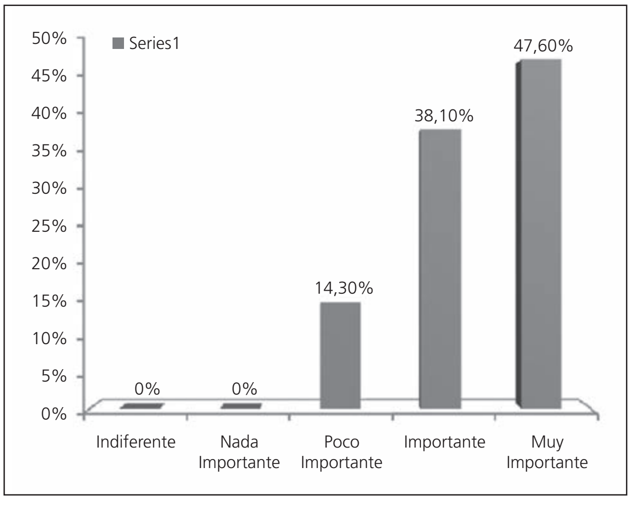
Situacion de pareja actual



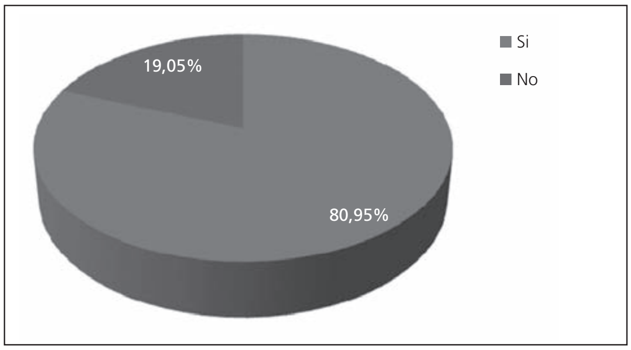
Pacientes que recibieron información sobre sexualidad por parte de algún profesional, previo al taller



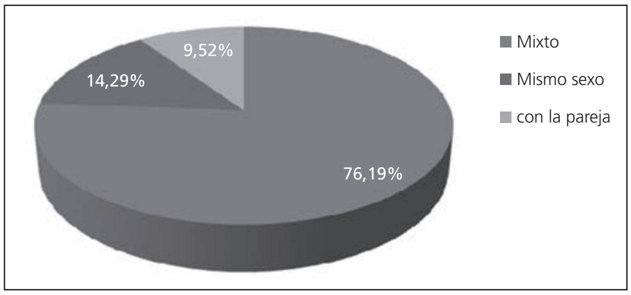
Grado de importancia de la sexualidad en su vida



Interés de participación de un taller de sexualidad



Preferencias sobre características de conformación del grupo



Se excluyeron aquellos pacientes que presentaran dificultades de comprensión.

A partir de los resultados obtenidos en las encuestas, se determinó la siguiente modalidad de abordaje: el taller se llevó a cabo durante un mes con una frecuencia semanal de una hora y media de duración cada encuentro, no superando el número de 15 participantes. Se conformo el grupo sin distinción por género, edad, ni diagnóstico. Fue coordinado por un equipo interdisciplinario (terapistas ocupacionales, psicólogo y fisiatras). En cada encuentro se plantearon disparadores para promover el debate y el intercambio de opiniones en un marco de respeto hacia la diversidad. Se incorporaron actividades prácticas relacionadas con el autoconocimiento, con la expresión sexual, asimismo en cada encuentro se les brindó información clara y precisa sobre aspectos clínicos/ farmacológicos y se respondió a preguntas surgidas en el momento. Una vez concluidos los encuentros, se efectuó una encuesta anónima de satisfacción a los participantes.

Resultados

Al taller concurrieron 15 pacientes, 10 masculino, 3 femenino y 2 transexuales, cumpliendo con un 70% de asistencia.

El promedio de edad fue de 41 años, del total de participantes 14 se encontraban internados y 1 recibía atención por consultorios externos. En cuanto a los diagnósticos, 10 de ellos presentaban daño cerebral adquirido, 4 con lesión medular y 1 con polineuropatia.

Del total de los pacientes, solo el 17% resultó tener pareja estable.

Los datos de la encuesta final de satisfacción fueron los siguientes: el 86% de los participantes respondió que a partir de los encuentros adquirió mayor conocimiento sobre la sexualidad en general y más sobre su propio cuerpo, el mismo porcentaje refirió haberse sentido cómodo con el grupo. El 72% refirió haber adquirido mayor seguridad para encarar una relación, le permitió romper con prejuicios (propios y ajenos). En cuanto a la posibilidad de aplicación de lo aprendido en el taller, el 58% respondió afirmativamente. El 100% de los encuestados refirió que el taller cumplió con sus expectativas.

Discusión

Poder hacer un relevamiento sobre el desempeño sexual actual y premórbido fue de gran interés para nosotros, por ello fue que propusimos en una primera instancia utilizar una evaluación confeccionada por el equipo utilizando como modelo la evaluación "Derogatis Inventory of sexual functioning -DISF-". Al analizar los datos observamos que la mayoría de las encuestas estaban incompletas, principalmente en aquellos puntos que indagaban aspectos muy íntimos de la sexualidad; presuponemos que el factor pudor jugó un efecto negativo al momento de contestar las preguntas, así como también lo complejo y extenso del cuestionario.

Por ello es que propusimos un cuestionario simple adaptado a nuestra población.

La mayor cantidad de pacientes que asistieron al taller correspondió a los que estaban internados; esto pudo deberse a que en los pacientes ambulatorios las cuestiones de traslados y de horarios (fuera de su horario habitual de tratamiento) dificultaran su accesibilidad.

El menor porcentaje de la encuesta de satisfacción correspondió a la "aplicación de lo aprendido en el taller"; esto puede tener correlación con las características de la población (internados y mayoritariamente sin pareja estable).

Es evidente por los resultados obtenidos, que el taller cumplió con las expectativas de los pacientes, siendo éstas la búsqueda de mayor información, por lo que podemos concluir que había un desconocimiento sobre el tema y una necesidad insatisfecha que pudo ser abordada y canalizada por medio de estos encuentros.

Lo que pudimos observar fue que la participación de los pacientes fue aumentando en cada encuentro. Además cabe destacar que hubo una mayor respuesta hacia las actividades prácticas/vivenciales frente a las propuestas de debate.

Conclusión

La intervención de terapia ocupacional para el abordaje de esta temática es enriquecedora, porque se orienta a fomentar habilidades para expresar la sexualidad y desarrollar el reconocimiento del propio cuerpo, a promover la exploración, la elección y el desarrollo del comportamiento sexual, el cual está íntimamente relacionado con el bienestar emocional y social.

La repercusión sobre la esfera sexual que provoca la discapacidad motora permite concluir que: aunque en algunos casos la función sexual queda limitada, de ninguna manera llega a anularse, ya que la capacidad para obtener placer y bienestar y la posibilidad de mantener la comunicación con la pareja sigue presente.

Es por esto que el reajuste sexual debe contemplarse como parte de la rehabilitación integral, resaltando que la salud sexual repercute positivamente en la calidad de vida y en las relaciones interpersonales.

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AUSTRIA

New Master of Science in Occupational Therapy programme in Austria

In March 2012, the first cohort of Master in Occupational Therapy students started their studies at the University of Applied Sciences Tyrol (fh gesundheit) in Innsbruck, Tyrol, Austria. Eighteen occupational therapists are currently deepening their knowledge and expertise within the scope of this programme, which is the dynamic interaction of occupation, participation and health. The curriculum aims to promote an integrative learning process in the fields of current occupational therapy practice, theory and research. It is taught in German and in English by national and international lecturers, experts and scientists from occupational therapy as well as from other relevant disciplines. After two years of part-time course work, combined with blended learning and self-directed studies, the students will conduct a research project which is part of their Masters thesis. Overall, the Master's programme aims to strengthen best practice in occupational therapy and research as well as in other fields of expertise in which graduates are keen to engage in.

MSc in OT students at the University of Applied Sciences Tyrol (fh gesundheit) in Innsbruck are also members of ongoing research projects within the institution, e.g. in the field of health promotion, healthy ageing, barrier-free accessibility, and also occupational science, as well as occupation, participation and health-related topics for children, adolescents, and their environment. Cooperation, exchange and further development with other national and international Master in OT programmes are an integral part of the programme. This includes for example teachers exchange, joint research projects, and student collaboration.

The Department of Occupational Therapy of the University of Applied Sciences Tyrol (fh gesundheit) is also a member of the European Network of Occupational Therapy in Higher Education (ENOTHE) and aims to contribute within this network to a fruitful exchange among Bachelor and Masters programmes for Occupational Therapists in Europe. For more information please visit the website at: https://www.fhg-tirol.ac.at/page.cfm?vpath=master_lehrgaenge/ergotherapie

Contact: ursula.costa@fhg-tirol.ac.at; Ursula Costa, programme coordinator, University of Applied Sciences Tyrol - fh gesundheit, fhg - Zentrum für Gesundheitsberufe Tirol GmbH; Innrain 98, 6020 Innsbruck, Austria. T: +11 43(0)50/8648-4741, F: +11 43(0)50/8648-674741. www.fhg-tirol.ac.at

BULGARIA

The Association of Bulgarian Ergotherapists (ABET) was founded on the graduation day of the first qualified occupational therapists in Bulgaria – 2 October 2010. This achievement was acknowledged by the WFOT and the association was approved as an Associate Member of the organisation. Hanneke van Bruggen, Executive Director of ENOTHE, was a special guest at the foundation meeting. She was awarded an honorary membership for her outstanding contribution to the development of occupational therapy in Bulgaria.

The main activities of ABET in the first year were focused on the official registration, organisational activities and promotion of the profession. On 24 March 2011 a big Open Day for Occupational Therapy was organised in cooperation with the University of Ruse and Frontline Partnership (UK) with the aim to present the unique contribution of the occupational therapy profession to service users, employers and wider society. The Open Day evoked great interest and was attended by local authorities, non-government organisations, institutions, service users etc.

In November 2011 and March 2012 the association organised one-day workshops on Sensory Integration with a guest lecturer from the USA – Dr Elaine Struthers. They were attended by occupational therapy students and practitioners, other allied health professionals, medical doctors and parents from Ruse, Sofia and Varna. The training was a big success not only for the promotion of occupational therapy as a profession, but also for approving the significance of the association.

The main efforts of ABET are focused on opening new job positions and ensuring high standards of quality. The association wrote official requests to the Ministry of Labor and Social Policy and to the Agency for Social Support to include occupational therapists in the personnel of the social services for people with disabilities.

The second General Assembly, held on the 20 October 2012, stressed the importance of the working groups. All three groups for promotion, professional standards and project work, have already met and planned main activities for the year.

The whole occupational therapy community in Bulgaria, graduates and students, was actively engaged in promoting the World OT Day with picbadges, cover art images and information in Facebook.

Liliya Todorova, WFOT Delegate Bulgaria

CROATIA

Croatian OTs fight for safekeeping of OT profession – Due to economic crisis affecting Croatia, the Croatian Government decided on widespread cuts in the public sector, which includes also cuts in the health and social care system. Cuts were necessary because of the large State deficit but they were not done based on population needs and equality. In a lot of hospitals, centres, institutions there is a lack of occupational therapists (OTs) and some occupational therapy (OT) posts are held by people who are not qualified occupational therapists but there is no or rather a small number of new employed OTs. Also a big problem appeared as there is no government funded internship for newly graduated OTs, which is obligated for them and defined by Law on Health Care. So, a rather big group of newly graduated OTs are not receiving the opportunity to register and obtain their licence to work as they cannot do their internship. The Professional class for occupational therapists within the Croatian Health Professions Council and Croatian Association of Occupational Therapists have and will take all available actions to influence policy makers on the importance of occupational therapy in sustainable health and social sector.

Croatian Health Strategy 2012-2020 – During 2012 the Croatian Ministry of Health has been developing a new Croatian Health Strategy 2012-2020. Several OTs from the Croatian Association of Occupational Therapists and Professional class for occupational therapists within the Croatian Health Professions Council have been lobbying for implementing more OT services for Croatian population. The result is the new Health Strategy 2012-2020 in a part defining Health Professionals states that the number of OTs is insufficient especially considering standards in EU countries which needs to be changed as soon as possible. Lobbying was based on the WFOT Human Resources Project 2012.

Professional auditing – Professional class for occupational therapists within the Croatian Health Professions Council conducted 2nd professional auditing in several hospitals institutions/health and social sector which resulted in concrete evidence in what conditions OTs work as well as the still present irregularities, such as: insufficient number of OTs per patient and in view of the definition by the Ministry of Health Regulation on minimum requirements in terms of space, workers and medical-technical equipment for health care, some of the occupational therapist positions are held by people who are not qualified occupational therapists which is contrary to article 46. and 86. Law for Health Professions (Official Gazette NN 87/2009), limited spaces for occupational therapy, limited access to medical records of patients for OTs. Professional class for occupational therapists within the Croatian Health Professions Council has informed the Ministry about this in written reports as defined in Croatian Law on health care, and we are now waiting for their response.

Annual and electorial assembly for the mandate 2013-2017 – In December 2012, the Croatian Association of Occupational Therapists had an annual and electoral assembly which included positions of President, Honorary Secretary, Workgroup Coordinators, Delegates/Alternates for COTEC and WFOT.

World Occupational Therapy Day 2012 – The Croatian Association of Occupational Therapists has organised a small gathering and raffle for all the national association members on 30 October to celebrate World OT Day. National association members from all around Croatia have exchanged experiences and had fun.

Foundation of the Croatian Rehabilitation Alliance – In June 2012 the Croatian National Federation of Nursing, the Croatian Association of Occupational Therapists and the Croatian Society of Physiotherapists have established Croatian Rehabilitation Alliance. Saša Radić has been appointed as the Vice-President of the Alliance. As community based rehabilitation (CBR) is still in early development with joint efforts of the Croatian Rehabilitation Alliance members we hope to have more stronger and influential voice in society for implementation of CBR principles.

Workshop "Occupational therapy report writing" – Professional class for occupational therapists within the Croatian Health Professions Council organised two day Workshop "Occupational therapy report writing" in September 2012. The Workshop provided more than 30 Croatian occupational therapists with the acquisition of theoretical knowledge and practical skills needed for writing RT reports/opinions. The Workshop was successfully lead by Elizabeth Waterman, occupational therapist from Britain.

Occupational therapy assessment and intervention on feeding, eating and swallowing in paediatric re/habilitation – In June the Croatian Association of Occupational Therapists organised courses on occupational therapy assessment and intervention on feeding, eating and swallowing in paediatric re/habilitation. Vesna Cotic Costello OTR/L, an occupational therapy lecturer from the USA came for another professional visit to Croatia. The Workshop was intended for occupational therapists, speech therapists and doctors of medicine. We shared knowledge and experiences and gathered more insight on the topic. We are hoping for future collaboration.

Saša Radić, WFOT Delegate Croatia

FRANCE

The French Association of Occupational Therapists (ANFE) is 50 years old. We celebrated it through a new dynamic visual identity, a new office, a new organisation and a new breath.

The ANFE has never been so young and ready to defend occupational therapy in France.

The ANFE is pleased to inform you that it organised the second "National Week of Occupational Therapy" in France from 22 to 27 October, 2012 in links with the World OT Day. More than 50 events around the topic of "Accessibility" were held in many cities everywhere in France.

The ANFE is also pleased to announce a special issue of its journal named "ErgOThérapies". This special issue printed in June 2012 consists of two parts. One book of 96 pages is about "OT in Africa" with articles in French (English title, key words and summaries) written by occupational therapists working in Africa. The second book is the best thesis (Bachelor level) of the year 2011 which was chosen by a jury and was awarded during the General Assembly of our association in December. This year, the subject of the thesis is the using of the Kawa Model.

Rozenn Botokro, WFOT Delegate France

GREECE

On 29 September, 2012, the 2nd ELSITO (Empowering Learning for Social Inclusion) full day Seminar-Workshop under the title: **"Doing Social Inclusion"**, took place in Athens; the Hellenic Association being one of the organisers. One of the innovations of the above seminar is that the service users were members of the organizing committee. ELSITO is a learning partnership involving the following institutions and organizations:

- Hellenic Association of Occupational Therapists, Greece
- Actenz, GGZ in Geest partner VUmc, The Netherlands
- Hogeschool-Universiteit Brussel, Belgium

The Hellenic Association of Ergotherapists celebrated the World OT Day on 27 October 2012 by organising a series of promotional actions. A leaflet titled 'Occupational Therapy in Plain Words', based on the WFOT's document 'Statement on Occupational Therapy' was drafted and it was distributed to service users, stakeholders and the wider public. Additionally, a document with promotional suggestions was sent to the Greek occupational therapists, including discounts or free occupational therapy sessions, dissemination of information in social networks, electronic distribution of the WFOT poster, decoration of the work areas etc.

On 31 October the Hellenic Association organised a protest outside the Ministry of Health. The Greek occupational therapists protested for fair payment, because the occupational therapy session is paid 1.23 Euros since 1991, with a limit of 8 sessions per month. They also demanded equal rights with physical therapists, who are paid 20 Euros a session and speech therapists who are paid 15 Euros a session. The Association Board members had a meeting with the Ministry General Secretary and he promised to look into the subject and to try to rectify this unfair treatment and devaluation of the profession.

In 2012, the 60th WFOT Anniversary coincided with the 30th Hellenic Association's birthday and for this reason the Hellenic Association uploaded on to its website a special anniversary poster-banner honouring the bonds between the two institutions. On 11 November 2012 the Hellenic Association held a General Assembly and the agenda included several items concerning the future of the profession in the dire economic environment. After the end of the session, the Association members celebrated its anniversary with a birthday cake with 30 candles.

Aris Papageorgiou, WFOT Delegate Greece

HONG KONG

The Hong Kong Occupational Therapy Association is proudly celebrating its 35th anniversary this year. A series of celebratory activities will be held throughout the year culminating in an Anniversary Dinner in November.

The HKOTA is happy to announce that it is joining the WFOT Premium Pricing Model to enjoy full WFOT Individual Membership for all its association members, including member access to the WFOT website as well as online WFOT Bulletin.

INDIA

With inspiration from the WFOT initiative, World OT Day was celebrated with great enthusiasm on 27 October 2012 by almost all occupational therapy educational institutions and All India Occupational Therapists' Association (AIOTA) Branches. The information on World OT Day, Revised WFOT Definition of OT and WFOT Photo Competition Launch were uploaded on AIOTA website www.aiota.org for information to members and others.

The 50th Golden Jubilee Conference of All India Occupational Therapists' Association, that is, OTICON'2013 was organised at Trivandrum (Kerala) from 26-28 February 2013 with the theme 'Research Informed Occupational Therapy in Healthcare'. Renowned Pediatric OT – Ms Toni Thompson (USA), delivered the Keynote Address encircling the theme of the conference. Other eminent overseas guest speakers included: Ms Mari Butler (New Zealand), Nathan Vyatlingam (Malaysia), former WFOT Vice President, and Dr B.D. Dasari (UK). For more information, visit websites www.aiota.org and www.oticon2013.com.

Academic Council of Occupational Therapists of AIOTA organised "Continuing OT Education" in the form of a certificate course on Physical Agent Modalities – As an adjunct to OT at Santosh Hospital, Santosh University Ghaziabad from 21-23 December 2012.

ICCPDM: The International Conference on Cerebral Palsy & Developmental Medicine was organised at Lucknow from 8-10 March 2013. The AIOTA is scientific partner to this event. For more information visit the website: www.indiancerebralpalsy.com

Indian Journal of Occupational Therapy [IJOT], a peer reviewed journal is available as full text database from the year 2001 onwards on www.medind.nic.in. Now Vol. 44 Issue 3 is in process. Visit the AIOTA website www.aiota.org.ijot for more information and Guidelines for Submissions.

Anil Srivastava, WFOT Delegate India

NETHERLANDS

At the General Assembly in April 2012 Mieke le Granse, Delegate for the WFOT, member of the Committee International Affairs, Lecturer and Coordinator of the German Bachelor educational programme in The Hogeschool Zuyd was awarded with the Astrid Kinébanian Prijs for all her excellent work for the profession. The Astrid Kinébanian Prijs is granted every two years.

On 3 July, the third (completely revised) print of Grondslagen van de Ergotherapie was published. The book, which describes the fundamentals of occupational therapy, was written by many occupational therapists in the Netherlands and Flanders (Belgium).

In September the Dutch Association Ergotherapie Nederland (EN) celebrated its 55 jubilee in the new office building in Utrecht. In 1957 the first association of occupational therapists was founded in the Netherlands. The Dutch Journal of OT, EM, Ergotherapie Magazine existed for 40 years.

EN has started a project group to investigate and organise criteria and a monitoring system for the first official specialisation in occupational therapy in The Netherlands. The specialisation will be in Occupational Therapy with Children.

EN has nearly completed a new qualification certificate system. This system will be organised on three levels and focuses on evaluation of competencies of the occupational therapist as described in the (new) Professional Profile:

1. self evaluation
2. evaluation between colleagues
3. audit by independent authority

This certification will be important for assessing the quality of the individual occupational therapists and this certification process will generate extra credit points for the national paramedic qualification register (KP). The KP registration is based on credit points for life-long learning activities and working experience.

In October 2012 the Committee International Affairs of EN participated in the ENOTHE Annual Meeting in Vilnius with a Market place to discuss how National Occupational Therapy Associations and Educational institutes organise internationalisation in their association, curricula and research. Special attention was given to World OT day.

The Committee will have the same presentation at the National Occupational Therapy Congress in November to raise awareness for the importance and benefits of international occupational therapy work.

In November the General Assembly will be held in connection with the National Occupational Therapy Congress in Utrecht. The theme of the congress is Practice Based Evidence.

Mieke le Granse, WFOT Delegate Netherlands

ROMANIA

A movement is taking place towards an adequate recognition of the occupational therapy profession in a country dealing with reforms and transition to European values. Romania became an Associate Member of the WFOT in 2012.

The national context

Most of the formal reports and statistics on social inclusion places Romania at the bottom of Europe and highlights the causes of the situation: political instability leading to lack of responsibility and the absence of undertaking projects of wide scope. The bureaucratic heritage and the lack of the coherent legal framework for the topic look to be important reasons for this delay, as well.

The beginnings of occupational therapy

Soon after the 1990, occupational therapy gained a lot of sympathy and appreciation in the social care services due to the process of de-institutionalization and the volunteer Occupational Therapists from western countries supporting the disabled children re-integration. Different specialists started to promote occupational therapy in our country within different settings (special schools, hospitals, non-government organisations, foster care houses, social care institutions, etc.) – after an informal and short-term training. Currently, there are more and more non-government organisations and public social-medical services for the persons with disabilities that include occupational therapy among their services.

The current academic situation

After the year 2000, when more professionals involved in disability issues were trained abroad, the need for the profession of occupational therapy similar to European developed countries became obvious in Romania, as well. One of the results of their endeavours was the FPYPDEE[1] project launched in 2003 and its outcomes:

- an occupational therapy post-graduate educational program at a level compatible to the rest of Europe;
- a higher level of public awareness concerning both the need of inclusion and the unique contribution of occupational therapy to this topic;
- four qualified Romanian occupational therapists at the end of program in 2007;
- the establishment in 2010, of the first Professional Association of Occupational Therapists in Romania (PAOTR) linked to international networks (ENOTHE and WFOT)[2];
- an Occupational Therapy higher education studies launched in October 2010, at the “Vasile Alecsandri” University from Bacău, with European Structural Funds under the TEORO project[3]; linked to that project two others universities, from Piteşti and Alba Iulia, started occupational therapy studies.

Challenges and actions for the professional body

During the years 2011-2012 we would say that one of the

PAOTR goals was and still is to unify thinking about the concepts and philosophy of occupational therapy and to create a link between the social care, health and educational services similar to European countries with tradition in occupational therapy. As a result, the actions of the PAOTR are designed to promote an accurate image of the profession are directed to:

1. the professional regulation, in compliance with the national and European legislation;
2. the transfer of information about occupational therapy to customers and beneficiaries by implementing projects targeting active social inclusion[2].

[1] www.enothe.hva.nl/projects/tuning/fpypdee/index.htm
[2] www.terapieocupationala.ro
[3] http://www.teoro.ub.ro/proiect/activitati/81-vizita-presedintei-wfot

Mirela-Carmen Burllău, WFOT Delegate Romania
Daiana-Mihaela Popa
Marinela Raţă

SOUTH AFRICA

2012 has been a year of both change and achievement for the Occupational Therapy Association of South Africa (OTASA) as we have continued to work on improving our effectiveness and efficiency. Ongoing work is being directed towards transforming OTASA into an organisation that is truly representative of all occupational therapy staff. To this end, we now have a public health sector representative on Exco and our membership has increased from below 50% in 2011 to 55% in 2012. We aim to continue this upward trend.

Two new portfolios have been added under the umbrella of the *Education and Research Standing Committee*, namely a research and an occupational science sub-committee. The intention of the occupational science sub-committee is to create a forum to promote the growth of research and educational practices focused on occupation and occupation-based practice, while the research sub-committee aims to coordinate, support and develop occupational therapy research.

An online system was launched for the South African Journal of Occupational Therapy (SAJOT) in 2011. The system allows authors to submit articles for review online and will make the journal more accessible to occupational therapists globally.

The draft documents for revision of the scope of practice for occupational therapy were circulated by the Board of the Health Professions Council of South Africa. These were discussed at our Council meeting in July and comments have been submitted to the Board.

The OTASA congress in Durban was extremely successful with excellent attendance and presentations of a very high standard. The next OTASA congress will be held in Cape Town in 2014.

The planning for the 2018 WFOT congress is underway. A number of planning events have been held in order to foster broad participation of South African occupational therapists. The next stage will be to engage occupational therapists from other African countries in a planning event that will coincide with the OTARG conference which is being held in Zimbabwe in 2013. Further details will follow in due course.

SWITZERLAND

In 2012, the emphasis was placed on the following topics:

- Broad access to the topic “Prevention and Health Promotion”
- Use of synergies and discover gaps for activities
- Establish and maintain a network with other professional groups and organisations.

Age-appropriate project “Health Promotion and Prevention” for aging people:
The project aims are:

- Awareness by occupational therapists of the potential in this field of work throughout Switzerland
- Promoting the development of content and organization in this field of work.

Cooperation with the German Project “TATKRAFT”

The DVE (German NA) leads a project “TATKRAFT – Healthy Age by Occupation”, a project on health promotion for older people. Two members of the Swiss Association Switzerland participated in a workshop “Introduction to the TATKRAFT Programme”.

They will participate in the evaluation of the relevant manuals and possibly also in the implementation of the program.

Profile for OT with MSc

We are in a broad discussion about the possible future roles of occupational therapists with master’s degrees. The Swiss Association maintains an intensive exchange with the Program Directors for Occupational Therapy of the three Universities for Applied Sciences as well with representatives from associations of other health professions. The aim is to integrate the Master of Science in the Health Professions Act and to give occupational therapists with master’s degrees a position in the discussions on new care models.

Finding new ways in primary health care

Since the primary health care will not be sufficiently guaranteed in future, the Swiss Association will cooperate with other professions to develop new ways for adequate psychosocial and medical support services.

Luzia Isenegger, WFOT Delegate Switzerland

UNITED STATES OF AMERICA

Hurricane Sandy hit the east coast of the US in late October, devastating parts of New Jersey and New York as well as inland states; with damages from wind, flooding, and fires. The American Occupational Therapy Association (AOTA) received a kind letter of caring and concern from the World Federation of Occupational Therapists, and we have engaged practitioners with information about occupational therapy roles in disaster relief and recovery.

The re-election of US President Barak Obama means that the *Patient Protection and Affordable Care Act* of 2010 will continue to roll out. The inclusion of rehabilitation and habilitation in the essential benefits package would expand occupational therapy services to more people. Implementation of the law will continue through 2016, during which time AOTA will continue to advocate to ensure that the interests of the occupational therapy profession and our clients are advanced and protected.

The *2013 AOTA Annual Conference* was held 25-28 April 2013 in San Diego, California. Of global interest was the International Breakfast speaker, Sue Baptiste, OT(Reg)Ont., MHSc, FCAOT, Vice President of WFOT. Her topic, entitled *A global narrative of appreciating health: Mind-body-spirit*, was enlightening. Posters with an international focus were presented immediately following the breakfast.

AOTA periodically conducts informal polls as part of its regular communication updates with members. In October, members were asked if they were "interested in practicing occupational therapy in other countries". One thousand four hundred members responded, the highest response AOTA has had to this type of poll. The results were highlighted on AOTA's *Checking the Pulse* blog using the expression "ridiculously interested" in the title line, which is a way of saying "extremely interested". AOTA members are encouraged to network about international issues via our *International Forum* on AOTA's OT Connections, but non-members are invited to connect as well. A list of networking links in which AOTA is involved can be found in its *Get Social, Get Connected* page.

Susan Coppola, WFOT Delegate USA

8th OTARG CONGRESS
ZIMBABWE 2013
PROMOTING OCCUPATIONAL THERAPY IN AFRICA

Theme: Promoting Occupational Therapy in Africa

VENUE AND DATES

Monomotapa Crowne Plaza, Harare, Zimbabwe: 19 – 23 August, 2013

BACKGROUND TO THE OTARG CONGRESSES

The OTARG Congress is the premier biennial gathering for Occupational Therapists in Africa and beyond. Policy makers, persons living with disabilities and other individuals committed to improving the quality of life of persons with disabilities are also welcome. The OTARG Congress provides an opportunity for OTs in Africa and beyond to examine current progress, evaluate recent scientific developments and lessons learnt, and collectively chart a course forward.

IMPORTANT DATES

Deadline for abstract submission	21 February, 2013
Notifications for accepted abstracts	31 March, 2013
Early Bird registration	31 May, 2013
Confirmation of attendance by presenters	30 June, 2013

CONGRESS REGISTRATION FEES

Category	Early Bird	Late Registration
OT Professionals	US$220	US$250
OT students	US$150	US$180
Other	US$300	US$350

OFFICIAL LANGUAGE OF THE CONGRESS: ENGLISH

FOR MORE INFORMATION

Visit the OTARG website at http://www.otarg.org.za for information on abstract submission, registration, accommodation and other updates. Contact Tecla Mlambo at teclamlambo@hotmail.com for any enquiries.

WFOT World Federation of Occupational Therapists

2014 Yokohama, Japan® WFOT 16th Congress

16th International Congress of the World Federation of Occupational Therapists
in collaboration with
48th Japanese Occupational Therapy Congress and Expo
18-21 June, 2014 Yokohama, Japan www.wfot.org/wfot2014

Dear Colleagues,
A big 'Thank You' to all who have submitted, and are reviewing abstracts for this significant contribution to the ***WFOT Congress 2014*** – the premier international educational event for the World Federation of Occupational Therapists.

We are excited to have received many abstracts from all around the world. These are currently being reviewed by an international team of volunteer reviewers. Team Japan will then put together all the abstracts into sessions and streams which will form a comprehensive and exciting Scientific Programme. We look forward to advising colleagues of the acceptance of abstracts in late July.

New for WFOT Congress 2014 – INAUGURAL 'WFOT Lectureship'. At this significant new event, you can hear from the Awardee of the very first 'WFOT Lectureship'. The Awardee (to be announced) will have made an outstanding international contribution to the profession through research, education and/or the practice of occupational therapy. The WFOT Lecture will stimulate and inspire you. ***Be there!***

There are many exciting opportunities awaiting you in Yokohama, the venue for the WFOT Congress 2014 and Japanese Occupational Therapy Congress and Expo. You can find information about Yokohama and the inspiring Congress Venue at the ***WFOT Congress 2014*** website www.wfot.org/wfot2014 . Did you know that the annual Japanese Occupational Therapy Congress and Expo regularly attracts over 4,000 Japanese occupational therapists? ***Come to Yokohama and meet your colleagues from Japan and all around the world.***

Please visit the ***WFOT Congress 2014*** website at www.wfot.org/wfot2014 for regular updates.

Volunteer Reviewers wanted: Please check our website!

IMPORTANT DATES

Abstract Submission:
Closed 30 April
Notification of Acceptance of your Abstract:
End of July 2013

Registration
Information will be available from April 2013

Sharing Traditions, Creating Futures