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**A WEB BASED PEER REVIEWED PUBLICATION FOR MENTAL HEALTH
PRACTITIONERS, CONSUMERS & APPLIED RESEARCHERS**

This private *NON-PROFIT* professional publication and associated web-based, information archive service is dedicated to the enhancement of practice, program development, program evaluation and innovations in mental health and substance abuse treatment programs worldwide. Its goal is to provide a public forum for practitioners, consumers and researchers to address the multiple service needs of patients and families and help determine what works, for whom under a variety of circumstances.

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Journal Information

This peer reviewed Journal was created in 1996 by practitioners, mental health program managers and mental health consumers to provide international practitioners, scholars and consumers with a forum to publish and discuss their work in program development, evaluation research, policy innovations, and therapeutic practices that have been successful in their particular region and cultures. IJPR is not associated with any university or governmental institution, nor is it part of any 'old boy' or other professional network. It was created to provide information to an international readership about issues related to psychosocial rehabilitation and associated topics.

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Preparing Mental Health Reform in Slovenia

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Abstract

The article describes major mental health problems in Slovenia and describes the steps done to change present inadequacy of mental health system organization. Psychosocial rehabilitation services organized in non government organization are stewarding the process of reform through promotion of rehabilitation values and through involvement of users and carers. Further development of services is to be enhanced with integration of psychosocial rehabilitation in educational curricula for mental health professionals with involvement of users as teachers in educational process.

Mental Health Reform in Slovenia

Mental Health Situation

Slovenia is a central European county with 2 million inhabitants, the northern part of former Yugoslavia. It is a country in transition with the national product of 760 USD per capita; 7.7% of it is used for health. Mental health care is institutionalised prevailingly in hospitals and asylums, with the exception of wide-spread and easily accessible outpatient psychiatric clinics .

The main Slovene mental health problems are: high alcohol abuse, high suicidal index, increasing outpatient clinics visits and overcrowded hospitals (Table 1, Table 2).

Table 1: Mental health indicators in Slovenia

Source: WHO: Slovenia HFA Data basis 1998

Indicator	1985	1990	1995	1997	1998
Share of pop. 0 -14 years (%)	21.9	20.5	17.9	17.1	16.7
Share of pop. ? 65 years (%)	10.0	10.8	12.5	13.1	13.5

Rate of unemployment (%)	1.5	4.7	7.4	7.1	7.9
Suicides 0-64 years/ 100,000 inhabitants	30.7	25.1	25.3	25.7	26.5
Cirrhosis of the liver/100,000 inhabitants	42.8	34.0	34.1	29.2	29.1
No. of hospital beds/ 100,000 inhabitants	632	604	575	567	562
No. of doctors/ 100,000 inhabitants	187	205	212	224	228
Mean duration of hospitalization (all hospitals)	12.4	11.4	10.4	10.0	9.5
Share of expenditures for health of GDP (%)	4.2	5.6	7.8	7.7	7.7

Notes: Psychiatry receives approximately one third of hospital health funds. The suicide rate is three times higher for men, in the age period around 50, among retired people and among the unemployed. People who commit suicide are often without psychiatric diagnosis; among diagnoses, alcohol dependence and psychotic disorders are prevailing. 20.9% of people who commit suicide have already attempted it previously.

Regarding care for patients with severe mental illness (SMI), Slovenian mental health system can be (shortly described) characterized by the following statements (Svab&Tomori, 2002):

- services for patients with severe mental illness are predominantly institutionalised;
- non-government organisations (NGO) that provide social support, employment and housing are growing;
- there is no community psychiatry available;
- privatisation of services is rapidly increasing, however, it actually does not contribute to outreach, comprehensiveness of treatment and registration of patients. These things were organized better in the previous (socialistic) system.

A national program for mental health has not yet been accepted in Slovenia. National programs for preventing suicide and dependence on alcohol and drugs, however, have been developed.

We still lack consensus on planning of mental health services for persons with SMI. Care plans for patients with SMI are poorly coordinated among psychiatric institutions, social services and non-government organizations that provide rehabilitation services (Svab& al., 2002). Moreover, there are some additional problems that have been discovered only recently:

1. The number of admissions of patients with SMI to the greatest psychiatric hospital in Slovenia, i.e. University Hospital of Psychiatry Ljubljana-Polje, which provides care for approximately 700,000 population is rapidly increasing Table 2: Number of hospitalizations: admissions and rejections of patients from 1995 to 2002

Table 2: Number of hospitalizations: admissions and rejections of patients from 1995 to 2002

YEAR	ADMISSION	REFUSAL	TOGETHER	DIFFERENCE REGARDING	DIFFERENCE REGARDING 1995 (%)
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				PREVIOUS YEAR	
1995	2319	340	2659		
1996	2457	275	2732	+73	73 (2.7)
1997	2422	305	2727	-5	68 (2.5)
1998	2589	308	2897	+70	238 (8.9)
1999	2599	281	2880	-17	221 (8.3)
2000	2710	344	3054	+174	395 (14.8)
2001	2870	380	3250	+196	591 (22.2)
2002 first 6 months	1424	324	1748 (annual expectancy =3496)	+246 (expected)	873 (31.4%) (expected)

Diagnostic structure of admitted patients is presented in Table 3. Differences between diagnostic groups regarding admission increase have not been evaluated. yet, but we can assume that social factors influence frequent re-admissions as well.

Table 3: Diagnostic structure of patients admitted to University Hospital of Psychiatry Ljubljana Polje in 2001

Diagnostic group (ICD 10)	MEN	WOMEN
	N (%)	N (%)
Organic mental disorders	94 (9.4%)	145 (12.3%)
Psychoactive substance abuse related disorders	323 (32.4%)	89 (7.5%)
Schizophrenia	274 (27.5%)	316 (26.7%)
Other psychoses	133 (13.4%)	252 (21.3%)
Mood Disorders	95 (9.5%)	264 (22.3%)
Neurotic Disorders	77 (7.7%)	117 (9.9%)

2. It also became apparent that mean duration of hospitalizations is relatively long (60 days) in the largest hospital department intended for people with severe mental disorders. The health insurance does not cover the total hospital costs and does not pay for patients staying in the hospital for more than 50 days any more. Therefore, the duration of hospitalization was administratively reduced to 48 days within a couple of months, due to a financial crisis of the hospital. The number of hospital beds has been decreased by 12% in a years' time. This actually means that many chronic patients were (quickly) discharged prematurely, most of them with no preparation.

The process of de-institutionalisation has started in Slovenia already 40 years ago when the majority of mentally ill patients were discharged to their families, asylums and old peoples' homes. The new de-hospitalisation is different only in terms of better public and users' knowledge about human rights and possibilities of rehabilitation. Education of patients, carers and professionals was implemented by ŠENT, the largest NGO service in Slovenia, and by some enthusiastic professionals who took part in the anti-discrimination campaign launched by ENT (Svab, 2000).

3. The number of outpatient clinic visits has increased by 100% in the last four years (Ministry of Health, 2002). The number of general practice visits due to mental health problems is rising as well.

4. We are witnessing major dissatisfaction of patients, their families (gathered in the National Forum of Relatives) and public (media) with mental health services. Psychiatric hospitals and asylums are often regarded as out-dated institutions violating human rights of patients.

Planning

The conference on Psychosocial Rehabilitation in the Community held in the capital of Slovenia in May 2002 was aimed to provide an overview of the present situation regarding mental health services for patients with SMI in Slovenia and to prepare a platform for development of co-ordinated mental health reform. It was organised by the NGO ENT and the Government Office for the Sick and Disabled. A large public event was prepared to enable discussion and search for possible solutions. It was opened by prominent politicians and attended by leading Slovene experts. In the first part several distinguished guests from World Association for Psychosocial Rehabilitation (WAPR) and World Health Organization (WHO) presented mental health reforms in Western and Eastern countries. The opening speech was held by Prof. Norman Sartorius, president of World Psychiatric Association. He stressed that stigmatisation of people with mental disorders is the primary cause of the low priority of mental health services all over the world and that governments, as the ultimate stewards of mental health, need to assume the responsibility for ensuring that these complex activities are carried out. One critical role in stewardship is to develop and implement policy.

Presentation of the mental reforms in some Eastern European countries (Romania, Bosnia and Herzegovina, Croatia) has shown that the institutional model is largely preserved and that these models are mostly inadequate. West Europe and the United States have developed a community care model with very different evaluation outcomes. De-hospitalisation is successful only with a highly integrated and politically supported reform implementing sectorization and definition of responsible actors at the individual and systemic level.

In the second part of the conference the Slovenian system of care was described by presenters from social work services, NGOs, user organisations, psychiatric hospitals, asylums and general practice (GP). The GPs state that mental health should be included in their training curricula to improve the effectiveness of the management of mental disorders in general health services and that the lack of GPs in Slovenia does not allow shift to community care yet. The Government Employment Office representative stressed that employment opportunities should be maximized regarding some successful programmes already established by NGOs.

Work should be used as a mechanism to reintegrate persons with mental disorders into the community. Users and carers stated their needs for support, education, financial needs and need for rehabilitation services and adequate information system.

The conference was concluded with a round table of participants representing psychiatric hospitals, Ministry of Family, Work and Social Affairs, Ministry of Health, Ministry of Education, The Government Office for the Disabled and Chronically Sick of the Republic of Slovenia, users' representative, carers' representative and a member of the government's group preparing mental health legislation.

The conclusions:

1. Psychiatric hospitals should take part in the process of de-institutionalisation with their staff, expertise and resources.
2. Ministry of Education is going to support educational programs for teachers and pupils to promote anti-discrimination and to provide programs for improving mental health of children and adolescents.
3. Ministry of Labour, Family and Social Affairs has already prepared a reform for developing community based social services and a reform in the system of financing that should be individualized and consistent with clients' needs.
4. Ministry of Health will gather a professional group to influence presently low accessibility and locality of mental health services and to influence an improvement in rehabilitation services.

5. The Government Office for the Disabled and Chronically Sick of the Republic of Slovenia, will coordinate the actions and support anti-discrimination programs.
6. Users appeal for development of employment services and for improvement of financial situation of the mentally ill.
7. Carers demand a comprehensive information system and participation in the process of reform.
8. The new mental health law that is now exclusively concerned with outpatient commitment will also implement patients' rights for rehabilitation (ŠENT, 2002).

Conclusion

Psychosocial rehabilitation movement in Slovenia is therefore actually leading the path to mental health reform in the country. The consequences of economically triggered de-institutionalization are to be buffered through establishment of rehabilitation services and with involvement of users in the process of reform. Further steps are in the hands of politicians, but public pressure is currently rising through media. We are aware that similar process has already happened in most western countries. The development of community based mental health reform should be therefore supported by international counselling. A parallel process of educational reform is needed as well.. Mental Health Europe and ŠENT are preparing an International Conference on Education for Mental Health: Education for Change in May 2004 to assess and plan education and training of professionals, users and carers in Slovenia. We believe that psychosocial rehabilitation knowledge, mission and experience should be integrated in educational curricula of social, medical and pedagogical schools and in educational programmes for users and carers.

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Correlates of Psychological Distress in Discharged Patients Recovering from Severe Acute Respiratory Syndrome in Hong Kong

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Abstract

Objective: To study the correlates of psychological distress of discharged patients recovering from severe acute respiratory syndrome (SARS)

Design: Cross section and correlational

Setting: Queen Elizabeth Hospital, Hong Kong, China

Patients: Forty-one SARS adult patients aged between 20-71 followed up at Queen Elizabeth Hospital

Main outcome measures: Measures of disruption areas, social support, anxiety and depression.

Results: After controlling for age, the number of disruption areas and the lack of satisfaction with social support were found to be significant correlates of psychological distress. High scorers on the anxiety and depression scales were found to report disruption felt in physical functioning extending to other areas of their lives.

Furthermore, these high scorers also reported a relative lack of satisfaction with the available social support.

Conclusions: The findings of the present study can be useful in the following three areas: understanding the nature of events contributing to the distress in discharged SARS patients, developing appropriate psychological intervention and assisting staff to effectively identify the need for psychosocial support for these patients.

INTRODUCTION

Severe Acute Respiratory Syndrome (SARS) is an acute atypical pneumonia believed to be caused by a previously unknown coronavirus¹. The situation presented by sudden onset of acute illness is often characterized by uncertainties that elicit significant emotional distress. Diagnostic uncertainties threaten the sense of security and future predictability. Such ambiguities can be especially stressful when established treatments do not yet exist for the condition under investigation. Even in cases where treatment appears effective, concern over side effects and other longer-term consequences can introduce further stress². In the case of SARS, some individuals are faced with the threat of death not only for themselves but also for their relatives. Some actually experienced the loss of significant others while struggling with their own survival. The recovery phase of those who managed to be discharged may continue to be punctuated with fears of possible recurrence of illness and the elusiveness of a complete recovery.

Maintaining psychological equilibrium while living with the aftermath of the sudden onset of a severe illness poses major challenges to individuals' adaptive capabilities³. Folkman⁴ has described stress in a deficit model in which demands made upon an individual exceed the resources available at any given time. Stress can include physical, psychological or environmental factors that can cause distress. SARS patients are faced with multiple stressful experiences that tend to fluctuate over the course of time. After recovering initially in the physical sense, other challenges begin to surface. These include uncertainties about the ability to return to the previous occupation and handle interpersonal relationships. A severe illness like SARS can cause major disruptions to valued and essential activities. The subjective sense of physical frailty and fatigue can also lower the perception of personal control to return to their previous lifestyle and functioning level.

SARS patients are also possibly challenged with social prejudice and negative stereotypes. The stigmatizing nature of SARS can be particularly severe as evidence indicates that the virus is primarily spread by close contact with an infected person although there is still a great deal of uncertainty about other possible modes of transmission. Moreover, there is no universally established treatment regime and the disease may reappear again⁵. The fears of contracting the SARS virus could potentially fuel the shunning of persons with SARS and anyone associated to them. Such negative attitudes can exist even in the patients' significant others. Thus, SARS can cause difficulties for the infected individuals

in getting the support they need. Social support has been argued to be important buffer to the negative psychological consequences of stressful experiences by enhancing self-efficacy and promoting recovery⁶⁻⁸. Social prejudice can be significant barriers to social and vocational rehabilitation.

Thus, the psychological distress caused by SARS is not only limited to the debilitating impact of the physical symptoms. Discharged SARS patients have a long way to go to cope with the intrusion of the illness causing disruption to various aspects of their daily functioning. Furthermore, public fears of the illness and social prejudice can cause difficulties in these patients in getting the help when it is most needed. Understanding the processes that shape psychological adjustment in this population can be an important guide for conceptualizing intervention. For routine screening purpose, the HADS has been administered with the assistance of nursing staff about one week prior to the present study.

About 90 questionnaires were distributed to SARS patients at their regular follow up the QEH clinic. A total of 75 completed questionnaires were collected from 47 female patients and 28 male patients seen on average of 54.61 (SD= 17.33) days after discharge from hospital. About 6.7% reported moderate to severe anxiety symptoms and 6.7 % reported depressive symptoms⁹. The purpose of the present study was to explore the psychosocial correlates of psychological distress in discharged SARS patients who agreed to take part in a follow-up interview.

METHOD

Participants

41 participants were recruited from 90 outpatients attending the SARS Clinic of Queen Elizabeth Hospital. At the time of their regularly scheduled appointments at the clinic, patients were invited to an interview with the clinical psychologist. After briefly outlining the purpose of the assessment and obtaining written consent, participants were invited to complete self-administered questionnaires.

Measures

Demographic and illness related factors: Demographic characteristics were collected through the questionnaire. These included age, gender, education, work status and marital status. They were also asked if they had witnessed any family member contracting SARS and whether they experienced bereavement due to relatives who died of SARS. In addition, the following information about the patients was obtained from the medical records: the length of hospital stay, admission into the Intensive Care Unit and results of the Six Minute Walk Test¹⁰ performed at about the same period. The classification system of the Six Minute Walk Test was adopted from Yu (unpublished data) with category 2 covering the range from the 30th to 70th percentile and category 3 covering the range below the 30th percentile.

Disruption Scale (DS)

Scales have often been used to identify areas of stress-causing disruption experienced by patients with acute onset of severe illness. Adopting from existing stress scales for severe chronic illness^{2,11}, 6 possible areas of disruption were identified for the present SARS patients: physical functioning, work/job functioning, interpersonal functioning, finance and social discrimination. There is one final item for participants to list any additional disruption areas they experienced that are not covered. The number of areas of stress is aggregated into a total stress count score with a minimum of zero and a maximum of six.

Revised Social Support Questionnaire (SSQR)

The SSQR¹² comprises 6 items tapping on the number of available others and degree of satisfaction for the particular kind of support stated in the question. The 4-point Likert scale ranged from “not satisfied” to “very satisfied”. The internal consistency of both dimensions was reported to be 0.90 and 0.93 respectively.

Hospital Anxiety and Depression Scale (HADS)

The HADS was chosen to provide a relatively comprehensive and sensitive measure of psychological distress. The HADS¹³ consists of fourteen items from which two independent scores are calculated for anxiety and depression. Ranging from 0 to 21 for each of the 2 scales, low scores reflect absence of anxiety and/or depression. The scale was partially validated in Hong Kong and the Chinese version demonstrated good agreement with the original English version^{14,15}. Research with cancer patients in Hong Kong indicated that the internal consistency was high for both anxiety and depression scales (Cronbach’s alpha = 0.90 and 0.79, respectively), suggesting that the HADS could be a valid measure of psychological distress for the local population¹⁵. Preliminary normative data had been obtained from a group of medical students¹⁴.

Statistical Analysis

Firstly, the following data was explored on a descriptive basis: demographic characteristics, illness-related factors, BSS, SSQR and HADS. Secondly, Pearson product-moment correlation coefficients were computed to explore the relationships between HADS on one hand and demographic characteristics, the illness-related and psychosocial variables on the other. Hierarchical regression was used to identify the most relevant correlates of HADS measures. Finally, an attempt was made to identify the characteristics of high scorers on the HADS.

RESULTS

Demographic characteristics and illness-related variables

Patients were seen on average 55.81 days (SD = 15.77) after their discharge from the hospital. Results obtained are summarized in Table 1.

Table 1.

Results obtained for demographic characteristics and illness-related factors (N=41)

Variables	Frequency (Percentage)	Mean (SD)
Sex		
Males	19 (46.34)	
Females	22 (53.66)	
Age (11.15)		35.85
20-29	12 (29.27)	
30-39	16 (39.02)	
40-49	8 (19.51)	
50-71	5 (12.20)	
Education (5.10)		13.19
Employment		
Employed	22 (53.55)	
Unemployed	19 (46.34)	
Marital Status		

Married	19 (46.34)
Single	18 (43.90)
Divorced/ Widowed	4 (9.76)
Witnessing a significant other contracting SARS	12 (29.27)
Bereaved of significant other who died of SARS	6 (14.63)
Bereaved of spouse who died of SARS	(4.87)
Length of hospitalization	28.17 (19.09)
ICU admission	14 (34.15)
Six Minute Walk Test	
Category 2	25 (60.98)
Category 3	16 (39.02)

Disruption areas and SSQR availability and satisfaction scores

Details are listed in Table 2. The number of disruption areas endorsed ranged from 0 to 6 with a mean of 1.70 (SD = 1.75). Of the 6 areas, physical functioning was the most frequently endorsed. Qualitative responses from patients suggested worries over the recurrence of SARS, the ability to recover completely and the side effects of medication. Over 20% of the patients indicated disruption in finance, work/job and interpersonal functioning. For the SSQR, the mean satisfaction with social support across 6 items was found to lie between “quite satisfied” and “only a little satisfied”.

HADS scores

The means and standard deviation are listed in Table 2. Using the cut-off score of 11 suggested in the manual¹⁴, 12.1 % were classified as moderately to severely anxious while 12.1% were classified as moderately to severely depressed. In terms of the specific items, about 73.2% of the patients reported at least occasionally feeling “tense or wound up” and “getting a sort of frightened feeling as if something awful is about to happen”. About 85.4% of the patients reported feeling at least sometimes “slowed down”. As these patients have undergone severe illness and intensive medical treatment, it is possible that the item on slowing down may be reflective of physical condition rather than actual depression. In other words, physical symptoms can mimic depressive symptoms¹⁶. Taking into account that slowing down may be reflective of physical condition rather than psychological distress, an adjusted HADS Depression score was calculated leaving out Item 8 and prorating the score on the remaining 6 items. Using the adjusted Depression score (Mean = 4.64, SD = 4.52), 9.8% of the patients were still found to have moderately to severely depressed symptoms.

Table 2

Results obtained for the Disruption scale, SSQR and HADS (N=41)

Variables	Frequency (Percentage)	Mean (SD)
Disruption Scale		
Number of disruption areas		1.71 (1.75)
0 area	8 (19.51)	
1 areas	22 (53.66)	
2 areas	0 (0.00)	
3 areas	3 (7.32)	
4 areas	2 (4.87)	
5 areas	5 (12.20)	
6 areas	1 (2.44)	

Nature of disruption areas		
Physical functioning	26 (63.41)	
Work/Job functioning	10 (24.39)	
Interpersonal functioning	10 (24.39)	
Emotional functioning	8 (19.51)	
Finance	11 (26.83)	
Discrimination/ Prejudice	5 (12.20)	
SSQR		
Availability of social support		3.04 (2.21)
Satisfaction with social support		2.73 (0.58)
HADS		
Anxiety		6.00 (3.74)
Depression		5.24 (4.39)
Adjusted Depression		4.64 (4.52)

Relationships of psychological distress to demographic variables, illness-related factors, disruption areas and social support

In terms of demographic variables, only age was found to show significant correlation with the HADS scores. No significant correlations were found between the HADS scores and illness factors including the length of hospital stay, ICU admission and the Six Minute Walk Test. On the other hand, the HADS scores were found to correlate significantly with the number of disruption areas and the SSQR social satisfaction score. However, the HADS score did not correlate with the social availability score (Table 3). In other words, higher anxiety and depression scores were associated with the number of disruption areas reported. On the other hand, lower anxiety and depression scores were associated with a greater level of satisfaction with social support.

Table 3

Results of bivariate correlation of age, number of disruption areas, social availability and satisfaction with HADS scores

	HADS		
	Anxiety	Depression	Adjusted Depression
Age	0.60**	0.64**	0.62**
Number of disruption areas	0.62**	0.69**	0.70**
SSQR			
Availability of social support	-0.07	-0.15	-0.12
Satisfaction with social support	-0.59**	-0.68**	-0.67**

**p < 0.01

Hierarchical regression

To reduce the number of predictors, only variables that showed significant bivariate correlation with the HADS scores were included in the regression analysis. The 3 independent variables included age, disruption areas and satisfaction with social support. The 3 variables were grouped into two blocks: age

and psychosocial variables. The psychosocial block included both the number of disruption areas and social satisfaction. Sequential regression was employed to examine the contribution of psychosocial variables to the HADS scores after controlling for age. Thus, age is entered as the first block and the psychosocial variables as the second block. The dependent variables were the HADS Anxiety and Depression scores. To bypass the possible content overlap between mental health and physical condition, regression analysis was also carried out for the adjusted Depression score that was prorated from the remaining 6 items after leaving out the “fatigue” item. After controlling for age, the psychosocial variables was found to contribute significantly to the HADS scores, accounting for 17.0% of the variance for the HADS Anxiety score, 24.4% of the variance for the HADS Depression score and 26.0% of the Adjusted Depression score. An examination of the standard beta coefficients suggested that both the number of disruption areas and social satisfaction demonstrated significant association with all the 3 HADS scores (Table 4).

Table 4**Summary of regression analysis for predicting HADS scores (N=41)**Regression analysis for predicting HADS Anxiety Score (N=41)

		Standardized Step 1	β coefficients Step 2	R	R ²	R ² change	F change
Block 1	Age	0.60	0.24	0.60	0.36	0.36	21.62**
Block 2	Psychosocial variables			0.72	0.52	0.17	6.52**
	Number of disruption areas		0.35*				
	Social satisfaction		-0.28*				

Regression analysis for predicting HADS Depression Score (N=41)

		Standardized Step 1	β coefficients Step 2	R	R ²	R ² change	F change
Block 1	Age	0.64	0.21	0.64	0.41	0.41	27.32**
Block 2	Psychosocial variables			0.81	0.65	0.24	13.09**
	Number of disruption areas		0.39**				
	Social satisfaction		-0.37**				

Regression analysis for predicting HADS Adjusted Depression Score (N=41)

		Standardized Step 1	β coefficients Step 2	R	R ²	R ² change	F change
Block 1	Age	0.62	0.17	0.62	0.38	0.38	24.23**
Block 2	Psychosocial variables			0.80	0.64	0.26	13.35**
	Number of disruption areas		0.42**				
	Social satisfaction		-0.36**				

* $p < 0.05$ ** $p < 0.01$

Characteristics of high scorers on the HADS

Those who scored at or above the cut-off of 11 on either the HADS Anxiety scale or HADS Depression scale were classified to be high scorers, suggesting moderate to severe levels of psychological distress. Five patients of the present sample scored above the cutoff for the Anxiety scale. Out of these Anxiety high scorers, three also scored above the cut-off for the Depression scale. Two patients scored above the cutoff for Depression but not for the Anxiety scale. All five (100%) Anxiety scorers and 80% of Depression high scorers are over 40 in age and are unemployed. One of them has recently lost her spouse in SARS. Three out of the four others reported that they had lost their jobs because of SARS.

In terms of the disruption areas, 80% of the Anxiety high scorers and 80% of the Depression high scorers reported as having more than one disruption areas. All the high scorers indicated having disruption in the physical area. In addition, 60% of the Anxiety high scorers and 80% of the Depression high scorers indicated disruption in the financial area. In terms of social support, 80% of the Anxiety high scorers and 80% of the Depression high scorers reported an average in the category of being “only a little satisfied with the available social support”. The pattern holds for the adjusted Depression score as 75% of the adjusted score high scorers who reported having more than one disruption area and being only a little satisfied with the available social support.

DISCUSSION

The present exploratory study documented in local SARS patients the association between anxiety and depression on one hand, and the number of disruption areas and satisfaction with social support on the other hand. The findings can be useful for at least three reasons. Firstly, it is important to understand the nature of the stressful events contributing to psychological distress in discharged SARS patients. Results suggested the most reported disruption included physical functioning, finance, work and interpersonal issues. All the patients scoring above the cutoff for HADS reported disruption in physical functioning. Most of them also reported an additional disruption such as finance or job issues together with the lack of satisfaction with social support. Thus, psychological distress could be caused by the “spilling over” of disruption in physical functioning to difficulties in finance, work or interpersonal issues.

Secondly, the correct understanding of the nature of the stressful events is essential in designing and tailoring appropriate psychological intervention for the distressed individuals. As patients reported many potential concerns related to tangible areas like physical, financial and interpersonal issues, individual psychological intervention should be provided in the context of a multidisciplinary team. Apart from dealing with the more traditional psychotherapeutic issues such as reducing negative thinking and instilling hope, patients should be empowered with the knowledge of where and how to get support with the tangible and practical issues.

Finally, the psychosocial correlates of distress among SARS patients can help frontline medical and nursing staff to effectively identify the need for further intervention. Patients may find it easier to talk about the disruption and social support rather than directly reporting anxiety and depressive symptoms. This can be a particularly important point as the suggestion of psychological and psychiatric disturbance may aggravate the sense of stigmatization and prejudice already experienced by many SARS patients. Thus, as part of the holistic screening procedure during follow-up, medical and nursing staff can ask patients about the disruption/ changes experienced in the daily lives as the result of SARS. Starting with the more familiar physical aspects, patients can then be asked about the concerns/worries in other aspects of their lives including finance, work and relationship with family members and colleagues. Finally, it is important to ask patients to indicate how satisfied they are with the available support. Following the results of the present study, the following can be indicators for referral of further psychosocial intervention. The first indication is the disruption extending from physical problems to other areas of their lives. The second indication is the suggestion of lack of satisfaction with the available social support.

It may be interesting to compare the present data on SARS patients with available data of other local patient groups. In general, the level of psychological distress was substantially lower than those found for the local Chinese patients with advanced cancer and pain of which over 50% had been found to be moderately to severely anxious and depressed¹⁶. Comparing with other patient groups in Hong Kong, the level of emotional distress of the present SARS patients also appeared lower than that of the newly

diagnosed patients with human immunodeficiency virus (HIV) cases of which over 10% had reported anxiety or depressive symptoms above the cutoff on the HADS¹⁷. In comparison with established epilepsy patients who have been diagnosed for over 10 years, although the anxiety level of the SARS patients appeared relatively mild, the depression levels were similar¹⁸.

Like SARS, both HIV and epilepsy can involve a rather sudden and traumatic diagnosis for the patient. Furthermore, patients with HIV and epilepsy may also have constant worries over physical deterioration or an imminent seizure attack. However, the chance of a complete recovery appeared higher for SARS patients than for cancer, HIV and epilepsy patients. Thus, it is perhaps not surprising to find that the level of psychological distress of SARS patients were lower than that for cancer, HIV and epilepsy patients. On the other hand, the infectious nature of SARS could be more complicated than that for cancer, epilepsy and HIV. The limited knowledge of the mode of transmission of SARS may contribute to the social prejudice and negative stereotypes. It is not surprising than the satisfaction with social support of the present SARS patients were found to be significantly lower than that for the epilepsy cases¹⁷.

The present study had certain limitations. The sample size was rather small and had come from one hospital. Basically, a cross-sectional design was used and no cause-effect inferences can be made. Furthermore, a longitudinal study is really needed to monitor long-term changes in stress and distress. However, the present study did document in a group of local SARS patients the relationship of psychological distress with disruption areas and the satisfaction of social support. Comparison of the present data has also made with available data on other patient groups. In particular, the relative lack of satisfaction with social support of the present group of SARS patients has been highlighted. The clinical implications of the findings are discussed in the context of developing appropriate intervention as well as assisting frontline staff in identifying the need for psychosocial support in SARS patients.

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Using Marijuana: Positive and Negative Experiences

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Abstract

The author presents positive and negative aspects of marijuana use, based on his personal experiences, as well as from his understanding of psychological concepts. Positive effects seem to fall under the concept of mood enhancement. Two negative experiences reveal personal marijuana effects usually not discussed. The author developed a phobia of driving on freeways, probably related to the second experience. Although the author gave up all drug usage in 1973, this phobia has never been overcome. Possibly, the phobia involves state dependent learning, which is discussed.

INTRODUCTION

Many people hold extreme views regarding drugs, especially illegal drugs. Anti-drug people often present a view of all illegal drugs as horrible and without any redeeming qualities. Often they use the word “abuse” rather than “use,” which is sometimes a sneaky way to indicate disapproval and condemn those who do not conform to their wishes (see Eisenman, 1991 and Goffman, 1963, on how people who do not conform are labeled as “deviants” are condemned). On the other hand, pro-drug people often present a totally rosy picture of drug use, perhaps in part to rationalize their own drug usage. Each side—pro-drugs or anti-drugs—seems to have prejudice toward the other side (see Lippa, 1994 for an excellent summary of the nature of prejudice).

Here, I provide a more balanced view, relating some of my personal experiences using marijuana, which involved both positive and negative experiences. While I spend more space here on the negative experiences, I am not concluding that marijuana is mostly negative. Rather, the positive experiences I present are well known while the negative ones are less well known. So, I spend more time discussing the negative experiences. Also, there are other positive and negative experiences associated with marijuana which I do not discuss, so this paper is not intended to be a full explanation of marijuana.

POSITIVE EXPERIENCES

In the 1960's and early 1970's I smoked marijuana for recreational purposes. I had many positive experiences using marijuana (which I no longer use). It seemed to enhance whatever I was doing, so that good things became even better. Making love, going on walks, or listening to music all seemed markedly improved if done after smoking marijuana. Thus, one reason I kept using it was that the use was reinforced by pleasurable experiences.

On the rare occasions when I used marijuana while feeling depressed, it seemed to make me more depressed. Thus, marijuana appears to be a mood enhancer, making greater the mood one is in, whether that mood is positive or negative.

NEGATIVE EXPERIENCES

I had two negative experiences with marijuana use, which are worth sharing. I would appreciate feedback from others about them, what they mean, explanations, etc. Incidentally, I gave up all use of marijuana, any other illegal drugs, and alcohol in 1973 and have not used any since. The reason was that the drugs often made me feel bad, so I decided that the good experiences did not make it worth while, when there were also some really bad experiences. For marijuana, beginning around 1972 it often made me feel dizzy and nauseated. On at least one occasion, I felt so dizzy I could not sit up in bed for more than about two seconds.

The following two experiences involve negative things that occurred in 1973 (a few months before I quit using marijuana and other drugs) while using marijuana. But, they also included positive things, such as the improved sound of music in Experience 1 and the general good mood that occurred in Experience 2 prior to getting on the road to drive to my class.

EXPERIENCE 1

I had 4 roommates in my large house. I was hoping for a loving, commune-type situation where we would all get along, but that did not work out. Instead, they broke into hostile groups, with two each on a side, and me in the middle. One roommate would get marijuana from a source, who provided powerful marijuana. Whenever I smoked this marijuana, I would first feel like I was going to throw up (although I never did) and then have strong effects. The particular powerful effect I recall was listening to music on my stereo, while lying down on my bed. I closed my eyes. The music sounded incredibly good. In fact, it was so good and so clear that I thought that it could not be music on a stereo player. The band must be playing in my room! Yet, I also knew this could not be. However, it was the only explanation that seemed to make sense. It was frightening to me, as well as aesthetically pleasing. After awhile, I opened my eyes and saw that the band was not in my room. I concluded that the great music perception was a marijuana effect. However, the experience was very powerful.

EXPERIENCE 2

Later that year, I had some regular marijuana (not the great music-inducing marijuana of Experience 1) that I smoked before having to teach a night class at a branch campus. I thought the effects would wear off by the time I had to teach, but I was, it turned out, wrong. As I drove from my house to get to the campus, I stopped for a red light and noticed that the car stopped behind me had a young man in it moving his lips. My first thought was that he was singing, which was probably the correct interpretation. However, I then decided that he might be angry at me (for some unknown reason) and that he was saying hostile things. This made me anxious. Then, when the light changed, I drove to the expressway I had to drive on, to get to the branch campus.

The cars on the expressway seemed incredibly close to me, and I feared an accident. This may have been the start of my "freeway" phobia, wherein I am, to this day, afraid to drive on freeways, expressways, interstates, and anything like them.

I have tried to overcome this specific phobia via counseling and via forcing myself to drive on the freeways, but nothing has worked. I remain limited in where I can drive. I also do not like driving long distances.

When I got to my evening class, I felt as if I would fall down while teaching. The only way to feel secure was to grab onto the place where the chalk was held, while I taught. So, I taught the class standing with my back to the blackboard, with my two hands behind me, holding onto the chalk container, lest I fall.

CONCLUSIONS

Experience 1 was a delusion, a false idea of the band being in my bedroom, generated by the marijuana. I was trying to make sense out of what was happening, viz., the music sounding so great.

Experience 2 involved a delusion of thinking that it was hostility on the part of the young man in the car behind me, distorted perceptions of the cars on the expressway which induced further delusions of danger, and the perceptual distortion of feeling I would fall while teaching. Of course, it is possible I would have fallen had I not held onto something. Or, perhaps, I would not have.

The experiences and my inability to overcome my freeway phobia may be an example of state-dependent learning (Bozarth, 1987; Calvert, 2003; Overton, 1962, 1991; Schulz, Sosnik, Ego, Haidarliu, & Ahissar, 2000). This was suggested to me in a personal communication from Charles Tart, a famous researcher in the areas of consciousness and transpersonal psychology (see Tart, 1990). I learned to fear riding on freeways while under the influence of marijuana. Perhaps the reason I have never been able to unlearn this irrational fear is that I have tried to unlearn it while sober, i.e. not under the influence of marijuana. But, state-dependent learning data might lead to the suggestion that you need to relate to the experience the same way you learned it, so it might have been best if I could have tried to unlearn my fear while being intoxicated on marijuana. I very much do not want to use marijuana today, since I have come to fear it, based on the negative experiences I had. Thus, I never attempted—and probably never will—to unlearn my phobia by being high on marijuana and trying to overcome my fear of freeway driving.

In sum, the experiences were very powerful and seem induced by marijuana. But, what is amazing, is that to this day I have a specific phobia involving driving on certain kinds of roadways, even though I understand what occurred while driving to my class on the expressway. Understanding alone is not sufficient to overcome the phobias. If I drive on freeways, expressways, or interstates, I feel trapped, and feel extreme anxiety.

Feedback would be appreciated. I would like to understand these experiences better. I would like to unlearn my freeway phobia, but my attempts thus far, including counseling, have proven unsuccessful.

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Do the mothers of stutters use different communication styles than the mothers of fluent children?

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Abstract

The communication patterns used between Turkish mother and her stuttering child, and her normally fluent child were investigated. A total of 20 mother-stuttering child pairs and 20 mother-nonstuttering child pairs participated to the present study. All mother-child pairs were administered a structured game to facilitate spontaneous speech. Commands, questions, critical statement, no response and interruption were studied as negative statements. Verbal praise and verbal acknowledgement were accepted as positive statements. Interaction times and total amount of words were also measured. A significant difference was found between both mother and children groups only in the total words used. No significant differences were found for any other communication styles. These findings suggest that the communicative behaviors of mothers of stutter children are not different than that of the mothers of nonstutter.

Introduction

Stuttering is described as a disorder of fluency and characterized by part-word, whole-word and phrase repetitions, interjections, pauses and prolongations (Hegde, 1995). Perhaps no

other speech problem has received more attention than stuttering. Wide variety of theories has been proposed based on the enormous amount of research findings. Some theories propose physiological factors for the onset of stuttering, such as bilateral hemispheric dominance (Curry & Gregory, 1969), right hemisphere dominance for speech (Curry & Gregory, 1969; Moore & Hynes, 1980), brain damage (Andrews, Craig, Feyer, Hoddinott, Howie, & Neilson, 1983; Shames & Raming, 1994), neuropsychological or neuromuscular dysfunction (Van Riper, 1990), laryngeal dysfunction (Reich, Till & Goldsmith, 1981), and central auditory dysfunction (Hall & Jerger, 1978). Data on the frequency of stuttering among relatives of those who stutter have led investigators to propose a genetic component to stuttering (Ambrose, Yairi, & Cox, 1993; Howie, 1981; Poulos & Webster, 1991; Yairi, 1983; Yairi & Ambrose, 1992). Others suggest environmental factors for both the onset and the maintenance of stuttering, such as communicative stress (Schulze & Johannsen, 1991), anxiety (Craig, 1990), personality and negative parent-child interactions (Egolf, Shames, Johnson, & Kasprisin-Burelli, 1972; Peters & Starkweather, 1989; Meyers, 1990).

Although the recent advances in imaging techniques have shifted our attention to the neurological and/or physiological factors for the onset or the cause of stuttering (Wu, Maguire, Riley, Fallon, LaCasse, et al., 1995; De Nil, Kroll, Kapur, & Houle, 2000), communication environment that the stutterer lives in may contribute to the maintenance of the stuttering. Moreover the communication environment that the stutterer child lives in may even play an important role in the success or failure of the speech therapy. Throughout the literature there are enormous amount of studies devoted to this issue. Studies done about communication patterns of parent and child generally focus on the negative or positive nature of the statements as well as the frequency of questions and commands that the parents used with their stuttering children (Egolf et al., 1972; Kasprisin-Burelli, Egolf & Shames, 1972; Langolis, Hanrahan & Inouye, 1986). Egolf et al., (1972) suggested that the parents of stutters used negative statements, such as verbal aggression, silence, and interruptions more excessively than the parents of nonstutters. In their study Kasprisin-Burelli et.al., (1972) found that the parents of stutters displayed more negative verbal interactions and interrupted their child more frequently than did the parents of nonstutters. Mordecai (1979) reported that the parents of stutters used negative verbal profiles more than the parents of nonstutters. It was also reported that while the parents of stutters do not allow their children to respond to a question before asking another question, the parents of nonstutters were generally more positive in their verbal interactions. Langlois et al., (1986) found that the mothers of nonstuttering children used significantly more statements (declaratives) than the mothers of stuttering children, and mothers of stuttering children asked more questions (interrogatives) and made more demands (imperatives).

The results of these and similar studies put the parents on target. As a result, parents became a part of the therapy processes of stuttering (Starkweather, Gottwald & Halfond, 1990; Kelly & Conture, 1991; Bonelli, Dixon, Ratner & Onslow, 2000). Specifically parents were advised to modify their speech behaviors and avoid asking questions or interrupting child's speech excessively when talking with their children (Nippold & Rudzinski, 1995). Egolf et al. (1972) manipulated the verbal behaviors of parents during therapy session and found that while children stuttered more with their parents than with the clinician at the beginning of the therapy, over the time their fluency with their parents increased. Budd, Madison, Itzkowitz, George, and Price (1986) found that there were more speech disfluencies in parent-child interactions than therapist-child interactions during unstructured conversation, playing a game, oral reading or discussing a task. However the amount of disfluencies was significantly reduced through participating in the therapy program in which parents were given information about the therapy process and about how they need to interact verbally with their children.

Therefore, it was suggested that through understanding the structure and patterns of communication in the family, the clinician could find the negative interaction patterns that cause maintenance of stuttering problem (Bergström, 1997).

However, contradictory results to these findings appeared throughout the stuttering literature. Meyers (1990) studied fathers', mothers', and peers' patterns of verbal behaviors when interacting with preschool stutters through video recording them while playing with the stuttering child. She found that the fathers and mothers of young stutters were produced significantly more positive and routine statements and fewer negative statements than peers in conversations with their children. Both parents also asked more questions than peers did, but peers made significantly more comments than parents did. On the other hand, no significant differences were observed in negative interactions, comments, imperative statements, questions, or interruptions used by the stutters when interacting with their fathers, mothers, and peers. In the preliminary analysis of the differential effects of instructions to slow maternal speech rate or simplify the speech when conversing with normally fluent children, Ratner (1992) found no significant differences between the effects of the slowing speech rate and simplifying speech.

Kelly and Conture (1992) compared the mother-stuttering child pair with the mother-nonstuttering child pair in terms of interrupting behaviors, speaking rates and response time latencies. No significant differences were found between two groups of children or between the two groups of mothers for any of the three-paralinguistic behaviors. Although some studies proposed that questions asked by parents may increase the amount of disfluency in the speech of the stuttering children when answering these questions (Egolf et al., 1972; Langlois et al., 1986; Meyers, 1990), Weiss and Zebrowski (1992) found that questions did not lead to more disfluencies in the speech of the stutter children.

Kloth, Janssen, Kraaimaat, and Brutton (1995) reported that the results of a multiyear prospective study with 93 monolingual Dutch-speaking mothers and their preschool children. Twenty-eight of the mothers were diagnosed as stutters and 65 of them had a stutter husband. At the initial examination none of the children had any speech problems. However at the 1-year follow up sessions 26 of the children were diagnosed as an incipient stutters and the experimental group of this study was made up of these children and their mothers. The main result of Kloth et al.'s study was that the communicative style and speaking rate of the mothers did not show evidence of serving as factors contributing to the development of stuttering among children. No significant differences were found between mothers whose children developed stuttering and mothers whose children continued to have a normal fluency.

Ryan (2000) reported research findings of stuttering and nonstuttering preschool children and their mothers for speaking rate, conversational speech acts, interruptions and linguistic complexity. No significant differences were found between two groups of mothers and two groups of children in speaking rate, interruptions and linguistic complexity.

To shed light on this ongoing controversy, Nippold and Rudzinski (1995) made a thorough critical review of the literature concerning the role of parents' speech behaviors in relation to their children's stuttering. In the review, they reported that there is a little evidence to support the differences between parents of stutter and nonstutter children in the way they talk with their children. Support to this conclusion came from Yairi (1997). He pointed out that findings on differences between speaking rates of parents of stutter and nonstutter children are mostly negative one and any differences in relative speaking rate are almost likely to reflect not the parent's behaviors but the child's.

Since the literature is composed of contradictory findings regarding to this issue it was aimed

to look at these verbal behavioral patterns all at once in the present study. Therefore, it is present study's aim to find out what would be the results with Turkish mothers and their stuttering children for commands, questions, critical statement, no response and interruptions as negative statement as well as verbal praise and verbal acknowledgment as positive statements. At first glance Turkish mothers would be observed as over protector, highly demanding yet ready to do and talk for their children (Akkök, 2000). Published research on verbal communication patterns of Turkish Mothers not even exist. Therefore, the present study was carried out to see whether the communication styles of Turkish mothers with their stuttering children are different than that of the mothers discussed in the literature.

METHOD

Participants

Participants for this study were 40 standard Turkish speaking mother-child pairs, including 20 children who stutter and their mothers, and 20 age and sex matched nonstuttering children and their mothers. Educational level of mothers was also matched. Children who were reported having hearing, articulation, voice, language, psychological/emotional, physical or fluency (for the nonstuttering children) problems were not included to the present study.

Stuttering Children: The 20 stuttering children, 18 boys and 2 girls, had a mean age of 8:9 (range 7:2-12:4). The mothers and stutters that participated in this study were selected from child psychiatry clinic of one of the University Hospital in Ankara and from private rehabilitation centers for communicatively disordered children. Mothers were contacted right after the initial evaluation for stuttering and asked if they would participate to the research study. Therefore none of the children had received stuttering therapy prior to the study. Mother's report and diagnosis by speech-language pathologist and/or psychologist were used as the criteria for inclusion in this group.

Nonstuttering children: The 20 nonstuttering children, 18 boys and 2 girls, had a mean age of 8:9 (range 7:0-12:1). These children and their mothers were recruited from different state primary schools in Ankara. If mother and school counselor had not expressed any concern about their speech fluency, these children were included to the study.

All children were subjected to the further evaluation by the speech pathologist and psychologist following data collection. They read 150 words written age appropriate material. Five or more within-word disfluencies out of 150 words were accepted as criteria for stuttering group, two or less within-word disfluencies out of 150 words were regarded as criteria for the nonstuttering group.

Data Collection and Instruments

All 40 children first interacted with the experimenter then with their mother during a structured experimental condition, which took approximately 5 minutes per child-experimenter pair and 10 minutes per mother-child pair. Data collection was completed in one session. To facilitate spontaneous speech two sets of pictures were prepared as puzzles. A famous Turkish singer's face was used as the first set by the experimenter to familiarize mother-child pair to the experimental condition. This picture was divided into nine big and easy to recognize pieces. A whole picture and the pieces of the same picture were used together.

The mother to carry on the experimental condition with her child used another set in 23 pieces. An "Athletic girl picture" in 14 pieces was used as a target figure together with nine pieces of an "Athletic boy picture" as a distracter in mother-child pairs.

The entire mother-child interaction was audio taped by using two high quality tape recorders (Sony TCM-313 Cassette-Corder). The verbatim longhand transcriptions of the records were done using Sanyo TRC- 8080 Memo-Scriber by the experimenters. A Mother-Child Verbal Interaction Assessment Form was prepared for this study. Items used in this form were obtained from different studies (Aragona & Eyberg, 1981; Campbell, Breaux, Ewing, Szomowski & Pierce, 1986; Golinkoff & Ames, 1979; Kelly & Conture, 1992; Langlois et al. 1986; Meyers, 1989; Meyers, 1990; Meyers & Freeman, 1985b, 1985c). Based on the information obtained from the literature the following items were included in the assessment form: Commands, questions, critical statement, no response and interruption as negative statements; verbal praise and verbal acknowledgement as positive statements, and interaction time and total words. A detailed explanation of these items was given in the Appendix A. Three independent trained raters then went over the transcribed speech. They coded verbal behaviors while they were listening the tapes by counting the number of commands, questions, critical statements, no responses, interruptions, verbal praises, verbal acknowledgements, total words, and interaction time used by both mother and her child.

Procedure

After the mother read and signed up the Fluency Research Informed Consent Form, she and her child had seated in a quiet room, free from distractions, containing a table and chairs. Then, the experimenter briefly explained the purpose of the study. The experimenter and the child seated at the table face-to-face across from each other while mother was observing them. The experimenter took the whole picture of the “face of the singer” and put the pieces of this picture in front of the child. Then the following instructions were given to the child: ‘Things in front of you are the pieces of a face of a girl. The whole picture of the face is in my hand. I am going to describe the face of the girl and you are going to put the pieces together according to this description. I cannot look at your picture and you cannot look at my picture until you complete the face of the girl. Your mother is going to observe us silently. After you complete this picture you are going to make another one with your mother. Are you ready? Let's begin’. Experimenter then started to the session. Same instructions were used with all children during this demonstration.

After the first part was completed mother replaced the experimenter’s seat. “Athletic girl picture” was given to the mother. The pieces of this picture together with some pieces of athletic boy picture were put in front of the child. The following instructions were given to the mother: “Pieces of this picture are in front of your child. You are going to describe this picture to your child and your child will put the pieces together depending on your description. You will not show your picture to your child and will not look at your child’s picture until the picture is complete”. Then the experimenter gave the following instructions to the child: “The whole picture of a girl is in front of your mother. Now, you are going to listen to your mother carefully and put the pieces together, like when you do a puzzle, depending on your mother’s descriptions. However, we mixed some pieces of another picture into the pieces of the girl’s picture to make the game more complex. Therefore, you do not need to put all the pieces together. You will not show your picture to your mother and will not look at your mother’s picture until you complete the whole picture”.

A screen was put on the table between the child and the mother to prevent them looking in front of each other. The experimenter stated that the session was going to be audio taped and sat unobtrusively away from the mother and child, and audio taped the entire session.

Data Analyses

To assess reliability of communication styles used by both mothers of stutters and nonstutters,

three independent raters coded the entire set of transcripts. Several sets of Kappa coefficients were calculated for communication styles used by both mother and children groups.

A series of two-tailed independent sample t-test were performed to compare the mothers of stutters with the mothers of nonstutters, and stutters with nonstutters in terms of questions, commands, critical statements, no response, interruptions, verbal praises, verbal acknowledgements, and interaction time. The corrected raw scores of all communicative styles for the overall amount of the verbal output were used for this analysis.

RESULTS

The Kappa agreement index of communicative items for mothers group was 0.73 for interruption, 0.58 for no response, 0.79 for questions, 0.65 for verbal acknowledgement, 0.63 for verbal praise, 0.85 for commands, 0.66 for critical statements and 1.00 for total words for the mothers of stutters. Kappa agreement for the mothers of nonstutter was 0.59 for interruption, 0.38 for no response, 0.84 for questions, 0.95 for verbal acknowledgement, 0.69 for verbal praise, 0.65 for commands, 0.87 for critical statements and 0.94 for total words. Based on proposed conventions for assessing the 'goodness' of Kappa by Fleiss (1981) values of 0.60 through 0.75 are considered good (interruptions, verbal acknowledgement, verbal praise, critical statements for the mothers of stutters, and verbal praise and commands for the mothers of nonstutters). Values between 0.76 and 1.00 are considered excellent (questions, commands and total words for the mothers of stutters and, questions, verbal acknowledgement, critical statements and total words for the mothers of nonstutters).

The Kappa agreement index of communicative items for children group was 0.59 for interruptions, 0.70 for no response, 1.00 for questions, 0.90 for verbal acknowledgement, 0.96 for interaction time, and 0.95 for total words for the stutter children. Kappa agreement for the nonstutter children was 0.65 for interruption, 0.60 for no response, 0.93 for questions, 0.88 for verbal acknowledgement, 1.00 for interaction time and, 1.00 for total words. Agreement was accepted as good for no response and excellent for questions, verbal acknowledgment, and interaction time and for total words for the stutter children. For the nonstutter children agreement was accepted as good for interruptions and no response, and excellent for questions, verbal acknowledgement, interaction time and total words.

Two-tailed independent sample t-test was performed to compare the mothers of stutter children with the mothers of nonstutter children as well as the stutters with the nonstutters for communicative analysis. Means, standard deviations and t-test results of corrected scores for the mother groups were presented in Table 1, and for the children groups were presented in Table 2. No significant differences were found for the all-communicative items for both groups with the exception of total words. There was a significant difference between mothers of nonstuttering children and stuttering children as well as between stuttering children and nonstuttering children on the total words used (Table 1 and Table 2). According to the results of the present study mothers of stutters used more words (Mean =177.43) than the mothers of nonstutters (Mean= 102.43), $t(38) = -2.156$, $p = 0.037$. Also stutter children used more words (Mean= 54.01) than nonstutter children (Mean= 23.7), $t(38) = -2.03$, $p = 0.049$.

Table 1. Mean and Standard Deviation Scores, and t-test Results of Mother Groups for Each Communicative Items (corrected scores)

Communicative Items	Mothers of Stutters (N=20) Mean <u>SD</u>		Mothers of nonstutters (N=20) Mean <u>SD</u>		t* value	Level of significance
Interruption	2.66	3.64	1.02	1.89	-1.781	0.083
No response	0.86	1.13	1.84	3.85	1.093	0.281
Question	14.84	16.14	13.53	16.34	-0.254	0.801
Verbal acknowledgement	3.12	3.60	4.39	10.79	0.497	0.622
Verbal praise	0.23	0.40	0.23	0.68	0.00	1.000
Command	7.45	14.55	3.46	4.05	-1.182	0.245
Critical statement	3.72	9.96	2.04	3.37	-0.713	0.481
Total word	177.43	143.28	102.43	60.58	-2.156	0.037

*df=38

Table 2. Mean and Standard Deviation Scores, and t-test Results of Children Groups for Each Communicative Items (corrected scores)

Communicative Items	Stutters (N=20) Mean <u>SD</u>		Nonstutters (N=20) Mean <u>SD</u>		t* value	Level of Significance
Interruption	9.45	19.07	12.18	42.36	0.263	0.794
No response	18.38	48.80	20.45	28.92	0.163	0.871
Question	11.59	13.81	26.71	84.23	0.792	0.433
Verbal acknowledgement	26.98	37.17	33.20	62.88	0.381	0.705
Interaction time (in seconds)	303.75	174.7	277.6	223.44	-0.55	0.588
Total word	54.01	62.41	23.70	23.49	-2.031	0.049

*df=38

DISCUSSION

The verbal behavior patterns of the mothers of stuttering and the mothers of nonstuttering children were investigated in the present study. Commands, questions, verbal praise, verbal acknowledgement, critical statements, no response, interruptions, interaction times and the amount of words were the verbal behaviors under investigation.

Although the neurological aspects of the onset of the stuttering are stressed more and more in recent literature, parental verbal behavior is often cited as a major precipitating and maintaining factor in the onset and development of stuttering as well. The basic assumption of the parental prone theories is that the parents use excessive amount of questions, interruptions and negative verbal interactions when talking to their stuttering children leading a stressful communicative environment for the stutters children. Therefore, parents are frequently counseled to avoid using negative verbal behavior with their stuttering children. Many programs for treating preschool stutters involve modification of parent child verbal interactions (Bonelli et al., 2000; Budd et al., 1986; Kelly & Conture, 1991; Starkweather, et.al., 1990). Even American Speech Hearing Association (ASHA, 1990) has addressed to this issue and the parents of young stutters were advised to speak more slowly, to avoid asking to many questions, to limit interruptions and criticism when talking with their children.

The results of the present study revealed that both the mothers of stutter and their stuttering children used more words than the mothers of nonstutters and their nonstuttering children. On the other hand, no significant differences were found in any of the other communication styles that the parents used between two groups of mothers or two groups of children. That means the Turkish mothers of stutters do not communicate differently with their stutter children than the Turkish mothers of nonstutters.

The results of this research parallel the findings of other studies (Kelly, 1990; Kelly & Conture, 1992; Meyers, 1990; Ryan, 2000; Weiss & Zebrowski, 1991, 1992) that also found that the parents of stutters do not differ in verbal interactions from the parents of nonstutters. There is, however, some literature suggesting that the parents of stutters differ in verbal interactions from the parents of nonstutters (Egolf et al., 1972; Kasprisin-Burelli et.al., 1972; Langlois et al., 1986; Mordecai, 1979). The present study was carried out in a structured experimental setting and in order to eliminate familiarization to material a self-made puzzle was used. Although this difference in research design between present and previous studies may have contributed to the present results, we believe that these differences are a true appearance of the population under investigation. Because it is quite possible that this experimental setting may elicit a reasonable stress environment both for mothers and children, however, even under these circumstances no differences were found.

Since the findings documented in the literature are contradictory, based on the results of the present study authors conclude that the effects of the parental verbal behaviors on the onset and or maintenance of stuttering are not as much important as it was thought. However one should not disregard the findings suggesting such effect. Rather, interpreting those results as an experienced difficulty when controlling their fluency by the stutters might be a better way. Therefore, we suggest that the focus of research related the onset and or maintenance of stuttering should move from the parental verbal behavior to another dimension. We also believe that this is the time to stop blaming parents for their verbal behaviors but approach to them more positively and increase their confidence that they can help to their children in learning fluent speech. Thus, the focus of therapy process of stutter children should move from

modification of parental verbal behaviors to the involving parents actively to the transfer and maintenance studies of fluent speech.

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Appendix A. Definitions of Communicative Items

Command: There are two types of commands. First one is a direct command, which is a direct, clearly stated order or direction in declarative form (e.g., put that part under the neck of the picture). The other one is an indirect command, which is an indirect suggestion or question-command that attempts to lead the child's verbal or physical activity (e.g., Will you put that part under the neck of the picture?) (Aragona & Eyberg, 1981).

Question: To Inquire or ask something to elicit information (e.g., did you find the legs? Did you finish the whole picture?). The listener is expected to respond either verbally or nonverbally (Langlois et al., 1986; Meyers, 1990).

Critical Statement: Utterances that state some kind of disagreement or comments using negative intonation, such as "Didn't you understand what I tell?" "There is not a yellow part in this picture". These interactions deny or disagree with the previous speaker, using expressions, such as "No", "You don't know", and so on (Aragona & Eyberg, 1981; Meyers, 1990).

No Response: Participants of a conversation ignore each other in silence, such as pretending not to hear, not to answer the other's question, and so on (Langlois et al., 1986).

Interruption: Interruptions are break in the continuity with a question or remark while the other person is talking. An interruption was counted if the listener began speaking before the speaker completed his or her utterance (Meyers & Freeman, 1985c).

Verbal Praise: Is a statement indicating verbal approval, encouragement and positive feedback about someone's behavior, such as "Yes, that is right", "That is difficult but you can do it", "Great! You did an excellent job", and so on (Aragona & Eyberg, 1981; Campbell et al., 1986).

Verbal acknowledgement: Is verbalizations, which contain no manifest content (e.g., "Okay, yes, all right"). These statements show that the listener accepts, approves, or recognizes the expressions or behaviors of the speaker. For example, mother's reply of "Okay" when the child says, "I find the legs of the girl" (Aragona & Eyberg, 1981).

Interaction Time: Total time of conversation between mother and child in seconds (Meyers and Freeman, 1985a).

Total Words: The amount of words used in a given time period.

Therapeutic Listening: a work instrument at the service of mental health?

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Abstract

This article approaches the question of relations established between the team and the users and intra-team, as factors that facilitate or make difficult the interventions in mental health. The thematic analyzed consisted of the centralization of actions having as its base a therapeutic relationship, as well as the importance given to therapeutic listening and to be present as a therapeutic instrument in everyday experiences. This study was developed at the Mental Health Community Center in São Lourenço do Sul/RS, Brazil, the so-called "Nossa Casa", taken as a practical mark in a new way to approach mental illnesses. This research consists of a qualitative study in which we make use of the Marxist referential, the dialectical materialism, as a theoretical substrate in order to interpret reality. The instruments used were semi-structured interviews with ten individuals from the mental health staff. It was concluded that intra-team relations and integration are decisive for de-institutionalization, which implies transformation of the professional roles in institutions, as well as centralization of the therapeutic work in the listening and in the validation of the user's identity appear as a work style of the Service.

The scenery of the study

This work was developed at the Mental Health Community Center of São Lourenço do Sul/RS. The institution is characterized by offering integral attention to mentally ill individuals, through a network of services of integral attention towards mental health. This institution comprises the following services: Psychological and Psychiatric Ambulatory, Center of Psychosocial Attention – "NOSSA CASA"- CAPs, the mother-cell of the project, Therapeutic Workshops, a Psychiatric Unit in the general hospital, Home for Children and Teenagers, "Nosso Lar" – Protected Home. The network is accredited by SUS – the Brazilian Health Public Service – and gives attendance to people from the urban as well as the rural areas of the city. The purpose of the service is communitarian attendance to mentally ill individuals under the perspective of Psychiatric Reformation. This is emphasized by the permanence of the person in his/her environment, integral attendance aiming to meet individual needs and the practices of social reinsertion and rehabilitation.

This is a qualitative study which uses the Marxism referential, the dialectic materialism, as a theoretical substratum for the interpretation of reality. Abstracting the issue of negation-overcoming for the referential of psychosocial rehabilitation from dialectic approach, I consider necessary to deny the assistance reality of the individuals with mental disturbs centered on the model of damage, deficit, toward the rescue of centralization of the focus on the abilities and the search of work to reach the aims of psychosocial rehabilitation, citizenship and quality of life. The interviewees are identified in the text by letter “A” and the number of the interview (for instance: A1, A2, and so on).

In this area I approach the relations established between the team and the users, and the intra-team. The centralization of actions, having a therapeutic relationship as its basis, is very concrete in the exposition of the actors, as well as the importance given to therapeutic listening and the fact of being present as a therapeutic instrument in everyday experiences. The assistance practice permeated on the responsabilization by mentally ill patients is evidenced by the interviewees’ speech. Negotiation, attention, respect, affection, validation of identity and freedom are seen as therapeutic processes that lead the users to an increasing in the quality of life.

The biggest referential, the biggest instrumental of this is the human relation. And for that, there must be good human relations of all work structure. If there is not, it does not work. It gets much harder. So this was the original idea of the creation of a service that is named “NOSSA CASA”. When the house is “NOSSA CASA” we are citizens inside it, and there is a flattening of hierarchies. This is the biggest secret (A1).

Through the speech, it is possible to notice the centralization of work in human aspects, regarding patients as much as employees. The flattening of hierarchies remits to the freedom of weaving suggestions, comments and interventions by the whole team. This flattening is a concrete reality; however it can be understood by at least two forms. Firstly, as a real horizontality in all instances, contemplating the aspects of doing and administrating the care. Secondly, I visualize that this flattening of hierarchies, many times, was used to fill in brackets regarding the physical presence of professionals, mostly the technicians. There was a technical necessity that the professionals present in “Nossa Casa”(technicians and non-technicians) could keep up with the attendance and the resolution of demands that were presented. In this case the flattening comes from an external necessity, related to making, the practice. In sum, it is a flattening derived from the convenience and/or necessity.

Saraceno, Asioli & Tognoni (1997) highlight the attitude of integration of the team as one of the several variables that determine the infirmity and/or the efficacy of the intervention. These variables, related to the organization and to the style of the work of the team, can be either favorable or unfavorable. They point to an integrated team as a favorable variable, that should have the following characteristics: distribution of power, importance of knowledge, clear and non contradictory communication; discussion and planning of the work, socialization of knowledge, self-criticism and periodic evaluation of the results. Among the factors that obstruct internal integration, the authors point out the practical separation between the different professional roles, the differences as to the levels of empowerment and cultural aspects of the professional roles, and the conflicts and frustrations among the members of the team.

I understand that “good human relations in all work structure” remit to relations not only among the users, but also over all among the technicians. What I could apprehend is that many new services meet serious difficulties and tensions among the technical team, commonly in relation to dispute of power regarding the coordination of these services.

In some cases the teams de-structure themselves (or are de-structured), seriously compromising the work developed. And while the professionals dispute power between them, the users are forgotten. That is, the service, constituted a priori for the user, ends up being a stage of dispute by the technicians, who should provide the care. Thus, the disintegration of the team constitutes itself in a variable that favors for the development of the infirmity, compromising the efficacy of the interventions.

According to Saraceno (1999, p. 95-96):

A high quality service should be a “place” (constituted by a multiplicity of communicative places/opportunities) permeable and dynamics, where the opportunities (that is, the resources and the negotiable occasions) are continuously available to patients and technicians. In fact, if from a service (of a fraction of it) the “endowment of “opportunities” is established in a limited dimension and once for all, the result will turn into a progressive blindness of that part of the service in relation to the attributions that he does not have [] the passage from “space” to “place” is a complex process that is concerned not only to the architecture but most of all to relations among people (affective and of power).

Other authors such as Ribeiro & Teixeira (1997, p. 336) point out that the disputes among professionals conduct to “sterile antagonisms and to political/epistemic disputes by knowledge/power, besides contributing for the fragmentation of subject-object of their interventions”. Despite the changes that have been processed in the country regarding assistance to mentally ill patients, the authors question “if the assistance effectively given has been transformed concretely toward the ethic values of our times”, independently of the theories or adopted techniques.

I would like to add Basaglia’s inquietudes (1991), where he emphasized that it is not the redefinition of the institution regarding structural terms, through new schemas, that will guarantee that the actions will be therapeutic, but the relations that will be established inside the new assistance organizations.

I understand that the new services should be attentive for possible (and concrete) contradictions that might configure in its interior. One of these contradictions refers to the discourse about the practice not to be suitable to the practice developed in many cases. It seems apparently easy to theorize about a good human relationship, however, I question: will this relation be operationalized in practice? Or it will get lost in the meanders of the power?

Basaglia postulates that the contradictions of the real should be dialectically experienced. He points out that if the contradictions were not ignored or postponed, in an attempt to create an ideal world, but faced dialectically, the community would become therapeutic. He highlights that, for this comes true, possibilities and alternatives must exist. Only this way the dialectic would exist.

It can abstracted that different authors call the attention for the relations established between people – professionals and users in the services, highlighting the importance of explicating the contradictions, as pointed out by Basaglia. Our concern while professionals, must be directed to the questioning of our praxis, in order to our everyday practices effectively correspond to practices ethically suitable with the philosophical principles adopted.

We have something in common, which is the ... the humanization of the service, that is to make him a person that can live again inside the community, to find his place, and that a person might live a happier life than the one he was having so far. I believe that these practices that we use ... they come to what we think ... which would be ideal for the human being. To receive respect, to receive the affection of the people and ... I believe that the time has showed us that ... these people somehow got to get reorganized (A8).

This speech is related to the human relationship established with the users. However, the individual under study makes a concrete reference to the practices developed, mentioning respect and affection. These attitudes certainly should exist in a good service of mental health. However, they cannot be constituted in the only alternatives offered. Undoubtedly the users need affection e attention, but they also need interventions that might provide concrete transformations in their lives.

Saraceno (1999) alerts that, in the internal integration of a good service, organizational and affective strategies should be contemplated. He highlights that the permeability of the resources and the knowledge should surpass the separation of them. I understand that this stage should constitute itself in the ideal to be reached by the services. The movements in the services, when conducted towards organizational and affective questions concomitantly, would lead to dialectic overcoming. The same way, when the conflicts and the contradictions

were dialectically worked, and not occulted, the discontinuity, the appearing of the new, would be promoted, and the explicitation of the contradictions will conduct to qualitative improveness that will process changes in the real life of the services.

... And I think that, in my opinion, the most important is ... we talk with all these people ... here in the house ... I am speaking about the user now. Talk to him a lot of conversation, a lot of conversation with the people, no need to impose anything, it must be like that, that must be like this, or like that. I think that ... of course everything has its limits, isn't it? But a lot of talk, I guess so. (A2).

To talk and to give attention are seen as interventions that result on the strengthening of the users. The negotiation with the users is established through "no need to impose anything". However, the interviewee states that sometimes there is the need to establish limits. The establishment of partnership with the family is seen as a positive factor, by the possibility to listen to what the family has to say about the user. Commonly this kind of intervention leads to a unique language, through which professionals and users establish a common approach. This leads to positive results for both, that is, families and users. Once the user will not receive information and different management, the family, on its hand, will feel supported by the team.

These people need a lot of attention. And it is this kind of attention that makes them to stay, as I said, they, they, have the courage to face the world that suddenly they have lost, I don't know the reason ... now they have ... most of the people who talk to us have got their families and ... and give their opinions too. So, this kind of thing, not to be only locked or interned, under medicine, things like that, this kind of thing does not help much (A2).

The interviewee has a clear understand that the confinement, the reclusion and therapies centered in psychopharmacology itself do not bring results for rehabilitation. He expresses lack of knowledge on the possible reasons that led users to get mentally ill. This statement corroborates with what was evidenced in the analysis of Wetzel (1995): the non-technicians would not need to know the scientific knowledge for their practices. Non-technicians realize this as a limiting factor, at the moment in which the knowledge is limited to some professionals.

I understand the importance of extending the knowledge indiscriminately to the employees. I highlight that the adoption of this behavior would only bring consistency to the interventions done. This homogeneity, kept the proportions, should not result in empty academicism and formalism, but attend demands for the practices not to become fragmented. As approached before, the knowledge is directly linked to power. The analysis of these relations becomes important in order to establish the understanding of this knowledge/power centered in the hands of few "enlighten" individuals. It is established, then, the distinction between intellectual and manual work. The knowledge constitutes itself in the only way of emancipating the human being.

The group is ... that user's stuff, he opens his heart, I guess this is one the things ... the important thing is to know to listen. I guess this is what they have. You sit and talk and discuss. And they tell you about their lives and you listen to. That is a benefit to everyone (A4).

The hand to hand, the contact, the talk, that really close thing ... very closely, to listen to people, is not simply someone who takes a kind of medicine, that is a number ... That is a person who has some difficulties that we ... can sit and talk to him/her, to listen to what this person has to say (A5).

Listening represents, under the professionals' conception, a benefit for the users because of the attention, availability of time, individualization and the other to be able to talk freely, to talk about his/her life, his/her fears, necessities and difficulties. This is visualized as highly therapeutic. The differential is to treat the "person". This implies to welcome the user in his/her subjectivity.

The fact of listening to the other, freely, is for Dewald (1981) a unique experience, in terms of significance and value. The author points out that the non-therapeutic relations are based on giving and receiving, in which it is implicit that each participant should show himself/herself interested by the other. On the contrary, in the psychotherapeutic situation the exclusive area of interest is the patient, his/her difficulties and problems. He highlights that it represents a privilege to have someone who listens to us and treat us with attention, respect and interest.

Andolfi (1996, p.71) highlights the availability as an important element to listen to verbal and non-verbal language. Listening, for this author means also the construction of a suitable and functional interaction. This is characterized by an external space (the setting) and the mental, internal space. The author highlights the importance of the silence in the therapeutic listening, conceptualizing that “listening means to suspend one’s own propositions and to allow the access of everything that comes from the other”.

Another important listening element, considered by Dewald (1981), is the therapist’s capacity of empathy, expressed through his/her capacity of putting himself temporarily in the patient’s place, when he manifests his thoughts and experiences. And through this experience to understand the meaning behind the material manifested by the patient.

Bezerra Filho (1987), analyzing the situation of psychiatric interview at the level of ambulatory attendance, describes important characteristics of the students’ listening compared to the diagnostic attitude. The author understands that the diagnostic attitude of the interviewer prevails in the teaching of clinics psychiatric practice, in detriment of an attitude of listening. He points out that a mentally ill patient, in his interpersonal relations, experiences invalidation of psychosocial identity, mostly when this patient is in an adverse social-economical context. Thus, in the process of listening, the patient is given the opportunity to realize himself as an individual, through the validation of his/her speech without discrimination, as a protagonist of his own history.

I consider that the real therapeutic involvement demands availability, interest, time, affection, and sensibility in the establishment of therapeutic relations. Without these minimum requirements, hardly the aspects concerned to psychosocial rehabilitation of the users, the way I conceive, will be accomplished in its totality. It matters, over all, an attitude centered in listening to the other, which reveals to be different from hearing, a physiologic function that demands a neurological constitution. In listening, we place ourselves in the objective external space and in the subjective internal space of the other, through an attitude of participation, of sharing the experiences, as well as being present in silence. Silence might acquire different meanings. I mean here the silence which denotes an attitude of acceptance, empathy, comprehension, establishment of a relation of trust. I consider these attributes fundamental substratum for the evolution of a rehabilitative project. “And, ‘to de-psychiatry’ the knowledge of psychiatric patient means not only release him of the limits of a diagnosis but also try to look for (re) meeting him while an individual of his own history” (Bezerra Filho, 1987, p. 123).

While the traditional practices transformed the mentally ill person into an object (and his body), new perspectives break up, in which the subjectivity is reintegrated with the social body of mentally ill patients. This consciousness about the importance of these interventions produces overcoming movements of the state of object in which the patient was relegated. And, corollary, the reconstruction of a physical, subjective and social body.

I think that ... I think it is this respect we owe them ... as citizenships. The respect we owe for the member of the family who comes here to ask for help ...because suddenly it is just to treat, give medicine, leave the patient like he is or put him in the hospital, if the attendance is not well given, we go there, to see what is not good (A6).

Well, the first thing, ..., is that we are concerned to treat mentally ill patient as a person that ... deserves all our respect, all consideration, and ... it is a relationship based on sound sense, in an affective attitude, ... and more, worried about ... the emotional of the person, that he/she has a, a ... a little of happiness, to bring a little of ... of encouragement for this person, and I think this leads to ... to a positive thought that ... that helps people (A5).

The respect to the user and his family is visualized through a concern and active responsibility of the welfare of both. A differentiation is done between symptomatic treatment, hospitalization and everyday accompaniment of the user in the service. The respect to the family is expressed in welcoming the mentally ill person. And, when feasible, this welcoming is not restricted to listen to him/her empathically, but to produce concrete actions that might change the context of life.

Respect, for Andolfi (1996), comes from the valorization of dignity and the unity of each human being. Respect transmission derives from a genuine sensibility and consciousness of the human being. Actions do not become valid if these components are not present. Respect is realized through the attention given to the person. The availability of the therapist is manifested through the importance given to the interlocutor's problem and the respect given to him. The author highlights that the differentiation of the symptomatic behavior of the individual represents a signal of respect for the client. Through this behavior, which remits to not reduce the individual to the symptoms that he presents, positive aspects and potentialities of the individual are reevaluated. Thus the author understands that on one side there is a person and on the other a symptomatic structure, as separated entities, in virtue of the individual's complexity to be much wider than his problems. Another dimension of the professional's respect, approached by the author, refers to the respect to the client's problem, when suffering and difficulties are realized, from the evaluation of the gravity under the client's perspective e not from prejudiced evaluations of the professional. This respect is expressed, as a last resort, when responsibility regarding actions performed occurs, differentiating those that are the therapist's competence and those regarding the client.

This active responsibility, sometimes, seems to exceed the limits considered adequate, when it results in excessive protection by the team, as characterized in the following speech:

They always feel very protective by us, and then, from that, we have to start to show them the world outside, how it is, what their necessities are, and what they need to do to feel well in their own houses. The necessity to work to have a better level of life (A10).

In the speech a paternalist attitude is evidenced, which becomes to be noticed by the professionals, when they recognize the necessity of a bigger independence of the users. To help, to get, to arrange are verbs that denote this situation. Even if one of the factors involved is economical difficulties of some users, I understand that an empathic attitude without being paternalist might be established and to accompany the user in the process of emancipation. I agree with Pitta (1994), when she states that the Centers of Psychosocial Attention should not be more than a passage place. The author points out that these services should always preserve non-permanence as a characteristic, but to welcome people when they need.

The attributions and limits of the professional, the user and the family were commonly discussed in the meetings of the team. While some defended a position considered more paternalistic, others assumed a position turned to the necessity of the user to face and to conduct his life. I understand that there must be neither an excessive paternalism nor an absolute non-responsibility. The attribution given only to the

user concerning the failure of some interventions, the non-responsibility, results in a very comfortable and convenient attitude for the professionals. We should provide help during the way, always visualizing the process of emancipation of the user. The sensibility to visualize/understand these movements might constitute in the differential between responsibility and paternalism.

It is not the big workshops that make the service better; I believe that are the small things done everyday, taking care of the user. It is the shoulder that, that permits ... permits the person uses in case of sadness. It is the word the person needs to hear to feel better. These are rehabilitative processes. To see the other as a human being and not a number or a figure that, by chance, came to our service. No, this person is a human being that according to his potentialities, his necessity might use one or another ... another rehabilitation process (A8).

It can be observed through this collocation that the attitudes considered relevant for rehabilitation are the welcoming, the listening to the other, and treat him as a human being. The interviewee recognizes that it is not the workshops that make the service better. Maybe because she recognizes that the workshops might constitute in entertainment places not in rehabilitative ones

I agree and recognize the importance of care, affection and welcoming. However, I consider that these are (or should be) intrinsic characteristics of the services of mental health that work under the context of psychiatric reformation. I visualize the necessity of, maintaining these characteristics, performing movements in the sense of performing real transformations in the life of the users, through the breakage of entertainment and the establishment of resources exchanges. In another way, the standardization of everyday activities that reproduce behaviors is promoted, creating chronification and blindness of the professionals regarding this problem.

I consider, just as Saraceno (1999) and Rotelli (1990), the necessity of breaking up with the entertainment and the necessity to practice de-institutionalization in any place, not only in the closed institutions. If the new services, countersigned in new practices, do not daily exercise rethinking their strategies in an open and clear way, might reduce rehabilitation to an attitude only affective to the users. This kind of attitude is, undoubtedly, important, however, it does not constitute itself in the only axle to be worked in rehabilitation. This question could be considered as a subjective question that involves rehabilitation. Nevertheless, I consider necessary to re-dimension the rehabilitation in the objective questions, the work in the axles house – work – social relations – family. To work both the objective and subjective questions simultaneously, in order to reach dialectic overcoming.

There is a great resistance in systematizing the actions from individualized therapeutic projects, as if systematization were an unnecessary bureaucratic impediment. I understand that individualized therapeutic projects should not be considered as merely normative processes, but as a set of norms and strategies that direct the actions. I understand that the lack of these projects compromises users' rehabilitation at the moment in which a set of strategies designed and upon them it is possible to evaluate the actions established for each user does not exist. Without this criticism, Psychosocial Attention Centers might constitute as permanent places, in which patients spend the day in a number of activities and go back home in the evening. The biggest difficulty, in this context, is leaving from a protected place. A project where rehabilitation is contemplated in a short, medium and long term might stop the "forgetfulness" of keeping a user indefinitely in the CAPS. As referred previously, these places should be characterized as passage places.

Saraceno, Asioli & Tognoni (1997) affirm that therapeutic measures (psychopharmacology, psychotherapy, rehabilitation techniques) cannot be employed in an isolated way, without the due psychological and social contextualization of the patient as well as the organization and work style of mental health service. The authors emphasized that any therapeutic intervention should be part of a

project that contemplates some features, such as: planned by the whole team, with clear and well defined objectives, performed by all members of the team and modifiable through the evolution of the results.

Saraceno (1999) raises the importance of the evaluation of actions in order to be able to identify which ones are relevant for the treatment and rehabilitation. In the absence of knowing which of these actions were really projected and developed, this evaluation is practically impossible. The author highlights that, when a set of interventions is successful for the user, the professionals signal them, and they attributed them to this or to that intervention, without clearness and evaluation. Thus, I highlight again the importance of minimum systematization of the services. I understand that the respect for the user also derives from the respect which his specific project is dealt with, unique of rehabilitation.

Through the interviews I could apprehend a certain difficulty regarding the description of the several rehabilitative practices used. While the workers of medium level point out some practices developed in a more concrete way, the technicians reported to the same practices in a wider, generic way. Here contradictions came up: the theoretical discourse not always corresponds to the development of its practice. The practices reported by technicians refer to those developed in the traditional paradigm: appointments, groups, meetings and the establishment of a human relation with the users.

I retake Kosik (1995) who, through the dialectics of concreteness, points out that the comprehension of reality only occurs at the moment the thought destroys the pseudo-concreteness. And under this destruction, relations like products of the man praxis are unveiled. The author highlights that the reality can be changed as we produce reality, and when we get aware that ourselves produce this reality. The destruction of pseudo-concreteness, through which the thought dissolves the fetishizing world ideal to reach reality, is obtained through the critics of praxis and the dialectic thought – which breaks the world of appearance to reach the essence.

We try to motivate them for ... life, we try to orient them in the space of time ... what else could I say ... it is so wide the activity that we do there that, sometimes, we miss words to put it. At last, I think that basically, what is done, is done with care, it is touching, hugging the patient, which is what they need more, in these hard moments, of difficulties, of psychic suffering [...] we motivate them, helping them, helping them in their everyday, and this takes time, and sometimes we get frustrated, but the answer comes (A10).

The interviewee above feels very compromised and takes active responsibility by this performance. Permeating all the process of the performed interventions, it is found an affective attitude. The interviewee sees this attitude as fundamental for the user in the hardest moments. The taking responsibility is expressed when he mentions the necessity to “motivate them for life”. This high level of consciousness, this takes responsibility by the user, brings a lot of frustration when the answers of the users are not those wished, over which the interventions were performed.

This is another side of the work developed with chronic mentally ill patients: the difficulties to satisfy to the demands designed by professionals. This takes to a feeling of failure, of impotence of the team, when, because several different interventions, the patient does not progress. I see the need to work the team, regarding these situations. On the contrary, this professional ends up assuming the failure of the interventions and, as the time goes, starts believing that it is not worth to invest on the user anymore, who has no conditions to get rehabilitated. Thus the user is placed aside and others, with “better conditions”, have the preference. Frequently we see professionals who formulate different explanations for that. This imposes a situation of acquiescence, of impotence, which might be contagious for the team, in its totality. This acquiescence, whether extended to the family, will corroborate to the hopelessness, normally already instituted by the chronic disease. I understand that the hope is the only

blessing we cannot take away from the families, since there are many families and people that can only face difficulties of having a mentally ill member inside the family thanks to hope.

Saraceno (1999, p.95) approaches the question mentioned above, when he claims that a high quality service must include all the patients. According to the author, bad services are those that establish hierarchies of intervention to the patients, according to the logic that “those who cannot now, will never be able to”. Thus, they end up being excluded inside the service. It is important to highlight that, according to the author, it is the patient that finds difficulties to adapt to the rehabilitation program but this does not mean he cannot be rehabilitated.

Final considerations

The centralization of the therapeutic work in the listening, in a respectful attitude, and in the validation of the users' identity, appears as a work style of the service. The relationship markedly human is considered as a rehabilitation factor for the users. I think that these differentials that are in the periphery of the actions, introduce qualitative improvements that are inserted in people's everyday life. However, if these characteristics assume a central role, in detriment of other aspects; rehabilitation turns to be reduced to an affective attitude. Undoubtedly this is important, but it cannot be the essence of the work developed. Dialectic overcoming is reached at the moment in which subjective and objective aspects from singular demands of each person are met together in the same historical individual.

Some contradictions are identified such as the inexistence of individualized therapeutic projects and structural separation between who executes rehabilitation and who gives treatment. This was evident in the speeches of the interviewees. While therapeutic attendants and nursing auxiliaries reported to the practices concretely, on the speeches of technicians prevailed a generality. Deepening these questions remit to resistances produced and to the negation of this reality. This evidence questions deeply the role of the technicians, and the deriving relations of knowing/power. As pointed out by the authors of the Basaglia's tradition, the de-institutionalization derives fundamentally from the changes in the established relations, which implies transformation of the roles in the institutions.

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“Recovering” Consumers and a Broken Mental Health System in the United States: Ongoing Challenges for Consumers / Survivors and the New Freedom Commission on Mental Health

Part I (of a two-part series):
Legitimization of the Consumer Movement and Obstacles to It

by

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1. The centers targeted for cuts include the National Empowerment Center (NEC) in Lawrence, MA; the National Mental Health Consumers' Self-Help Clearinghouse, Philadelphia; the Consumer Organization and Networking technical Assistance Center (CONTAC) in Charleston, W VA; The National Consumer Supporter Technical Assistance Center at NAMI, Arlington, VA; and the National Consumer Support Technical Assistance Center of the National Mental Health Association (NMHA) in Alexandria, VA.

Abstract

Since its anti-psychiatry beginnings, the consumer/survivor movement has succeeded in promoting its self-help recovery perspectives and gaining legal rights for patients. On July 22, 2003, the U. S. President's Freedom Commission on Mental Health advocated a *consumer-driven* and *recovery-oriented* mental health system -- a major coup for consumers/survivors. At the same time countervailing forces began blocking their efforts, challenging their accomplishments and promoting opposing agendas. This article is the first of a two-article series that examines how multiple counteracting forces have situated the psychiatric consumer movement today, either propelling it or trying to reverse its achievements in shaping the production of mental health services. This

part of the series describes how professionals came to embrace consumer/ survivor perspectives as well as attempts of oppositional forces to de-legitimize its gains early in federally funded initiatives of consumer run demonstration projects.

The next article (Part II of the series) will review the losses and gains to consumer initiatives resulting from a restructuring of behavioral health services in the United States under managed care. It will also examine recommendations of the Freedom Commission, and considers their implications for the social production of mental health services in a political environment where consumers/ survivors have lost legal ground in recent years.

Introduction

In July 2003, forty years after the federal government of the United States mandated release of thousands of institutionalized patients into the community, the President's New Freedom Commission on Mental Health (hereafter, Commission) declared the mental health system to be in shambles. The Commission recommended a complete revamping of the national mental health system to create access and integration of services oriented to recovery and consumer and family preferences (1). This is a major coup for the psychiatric consumer and ex-patient movement where the recovery concept was born. During the past three decades consumers and ex-patients (now called consumers/ survivors) "recovering" from the debilitating effects of their illness, institutionalization, and lost self esteem have promoted the value of peer support, (2, 3) and consumer run services built on it. The consumer/survivor movement has gained momentum in recent years, broadening its coalitions and finding vigorous support for its holistic vision of recovery, as evidenced both in the Surgeon General's 1999 report (4) and the newly released report of the Freedom Commission on Mental Health (1).

Since its anti-psychiatric beginnings, the consumer/ survivor movement has made significant gains both in promoting its recovery vision and in acquiring legal rights against long and unjustified institutionalization. However at the very point when consumer/survivor philosophies based on recovery are gaining public recognition and inspiring the reconfiguration of mental health services nationwide, countervailing forces began threatening to erode their gains. These forces -- an ideologically extreme wing of psychiatrists and family advocates -- have emerged at various times to oppose those who have questioned rigid biomedical perspectives and to promote easier commitment laws and coercive treatments. Given their strong backing by the pharmaceutical industry and direct access to the Bush Administration, they are powerful players against the progressive changes supported by the Freedom Commission. At no other time have contradictory ideologies and agendas been more active in trying to shape the production of mental health services and the treatment of its users.

This is the first of a two-article series that examines how multiple counteracting forces have situated the psychiatric consumer movement today, either propelling it or trying to reverse its achievements in shaping the production of mental health services. The articles pull from a number of different elements in the history of this movement, examining relationships its leaders developed with the mental health community, efforts and effects of oppositional forces at different times in its history, the impact of managed care, and the implications of the Commission report. This first article will briefly discuss the development of the consumer movement and the notions of recovery and community support. It will then trace the development of allegiances between consumers/survivors and professionals who learned of their perspectives, programs, and notions about recovery, promoted the production of innovative mental health plans, and enabled the eventual construction of the Commission's recommendations. I then examine two phases in the development of 13 consumer run demonstration projects and offer evidence of political interference from some of the same oppositional forces that are at play again today.

BACKGROUND TO CONSUMER/ SURVIVOR MOVEMENT AND THE COMMUNITY SUPPORT PROGRAM (CSP)

Ex-Patients/Survivors, Consumers, and Consumer Empowerment

The consumer/ survivor movement began in the late 1960s as a human rights movement (5 - 7) by anti-

psychiatric ex-patients who objected to institutionalization and treatments that deprived them of hope, independence and control over their lives (1). As they began to communicate with each other, many came to question biomedical assessments of the biological irreversible chronic nature of their disorder and need for lifelong reliance on psychotropic medication; others implicated iatrogenic effects of expert treatment and assessments (1). They lobbied against coercive treatment and institutionalization, respect from providers, and self-determination over treatment goals and outcomes. Today, as “survivors,” they continue to reject a biomedical explanation of mental illness, forced treatment and involuntary commitments, and lobby for increased material and social supports as a deterrent to mental illness. By the 1980s survivors were joined by “consumers,” who accepted the medical model of mental illness but advocated for community support. Both groups regard “consumer empowerment”-- based on self-determination and control -- as a corrective (9) to the indignity of forced treatment and involuntary commitment (8) and value mutual support for promoting personal recovery (10, 11). beyond measurable reductions in symptoms. Together they advocate consumer run services as self help alternatives or supplements to traditional mental health services.

Recovery

Judi Chamberlain, a pioneer of the anti-psychiatry movement had referred to elements of consumer empowerment and recovery in her classic story about the Consumer Movement (1). Recovery referred to proactively taking charge of one’s life and illness, in moving beyond chronicity. It related to changes in the self through empowering efforts to become self-reliant and satisfied in personal relationships and productive activities (12, 13, 14). Chamberlain has worked with researchers (16) whose technologies and workshops for professionals (17) have extended legitimacy to recovery as a guide for a successful rehabilitative model (18).

There are multiple models of recovery, however. Recovery in structured rehabilitation models (16) compares to looser notions of a process needing continual nurturing (19); both offer a learning perspective to cope with an ever present disease. These processual views contrast with recovery as an endpoint of completely terminated symptoms (18), a view backed by research showing complete remission of symptoms in deinstitutionalized patients (20, 21). However, it raises the ire of critics such as Torrey (18, 22) who consider it “dangerous” for raising false hopes.

Initiating the Community Support Program

The Community Support Program (CSP) was initiated in 1977 as an antidote to the deinstitutionalization of patients into the community without adequate support for them. It aimed to provide national leadership to integrate services at the state level and to help clarify lines of responsibility and funding at various levels of government. The leaders of the CSP sought a comprehensive model of community support based on a rehabilitative approach sensitive to client needs rather than to a strictly medical model of care (23) -- controversial for its time. The consonance of community support with the goal of consumer empowerment caught the attention of the administrators of the new Community Support Program (6, 24) and in 1984 the CSP identified self-determination (9) as a guiding principle of its Community Support Systems (25, p. 11). Depending on how far it deviates from the medical model, CSP continues to raise criticism from extremist wings of psychiatry and the family advocacy movement.

I. RELATIONSHIPS OF CONSUMERS/ SURVIVORS WITH GOVERNMENT OFFICIALS AND MENTAL HEALTH PROFESSIONALS

The Community Support Program

From its earliest days, the Community Support Program (CSP) enlisted consumer input, initially from families, but later from consumers and ex-patients as well. Consumers insisted that the interests of families as “consumers” did not necessarily represent their own (26, p. 35), since ex-patients objected to forced treatment and involuntary commitment while many families favored both. These differences in ideology between families and consumer/ survivors sharpened after families organized the National Alliance for the Mentally Ill (NAMI) (27, pp. 970-971), a powerful advocacy organization, in 1979 (6, p. 828).

Neil Brown and Jacqueline Parrish, chief officers of the CSP at the Center for Mental Health Services (CMHS) (2) were drawn to consumer self help and its compatibility with CSP's rehabilitative philosophy (24, p. 6). In 1988 they began funding consumer run demonstration services projects developed with state mental health program staff. These collaborations allowed consumers to share their ideas about service needs and their empowerment philosophy. It also led to the development of state-level Offices of Consumer Affairs which helped shape mental health policies and initiatives.

CSP also wrote federal laws mandating state mental health plans to include consumer alternatives (28) and to involve consumers in constructing their state's making mental health policy (6, p. 827). CSP arranged conferences between consumers and directors of mental health associations and other professionals on recovery. These meetings facilitated communication between potentially adversarial groups and allowed clarification, comparison of views, and possible collaboration.

In 2000 the CMHS established a Consumer/ Survivor Subcommittee to help guide the CMHS's powerful National Advisory Council on mental health policies. CMHS, however, has remained a controversial and marginalized government body, symbolically relocated from the more prestigious National Institute of Mental Health (NIMH) to the Substance Abuse and Mental Health Systems Administration (SAMHSA). It has been subject to particular pressure from lobbyists who disprove of its programs, and to the vagaries of changes in political administration.

The Mental Health Statistics Improvement Program (MHSIP) of SAMHSA

Through contacts at SAMSHA consumer researchers worked on developing consumer defined outcome measures, treatment goals, and a mental health research agenda (29; 30, p. 12). A task force convened in 1993 to develop the MHSIP Consumer-Oriented Mental Health Report Card, similar to one constructed by NAMI. With support from MHSIP, the Survey and Analysis branch of CMHS, and the National Association of State Mental Health Program Directors (below) consumer researchers and mental health professionals organized the Consumer/ Survivor Research and Policy Workgroup in 1992. The group has aimed for greater control over mental health research by reviewing grants and defining the content of proposal requests and review criteria.

National Association of State Mental Health Program Directors (NASMHPD)

Through contacts at the CMHS and mutual writing of CSP grant applications, consumer leaders came to know mental health program directors of their states. By the end of 1989, every director or commissioner signed the NASMHPD Position Paper on Consumer Contributions to Mental Health Service Delivery, which affirmed consumers' unique contributions to program formation and evaluation and in educating mental health professionals in their perspectives (31).

In 1993 NASMHPD established the National Association of Consumer/Survivor Mental Health Administrators to help state officers of Consumer Affairs deal with the competing demands of consumers/ survivors and bureaucracies. NASMHPD has also held annual conferences that have engaged consumer and non-consumer mental health professionals in dialogue. The organization has elicited consumer input and sponsored consumer-oriented research projects concerned with defining service outcomes (32).

Through increasing opportunities to meet with mental health policy administrators, program directors and other researchers, consumers entered a position gained earlier by the National Alliance for the Mentally Ill (NAMI), in guiding the national mental health agenda.

Support and Collaboration with the Research Community

Since the early 1980s psychiatry has become increasingly biomedicalized as environmental explanations for serious mental illness have gained disfavor (28). As a result, many ex-patients felt even more alienated from psychiatric ideologies and limited psychopharmacological interventions. At the same time, some mental health

research questioned the assumption of unremitting chronic mental illness (21), while others embraced social treatments rather than conventional views emphasizing medication (34) or questioned the effects of antipsychotic medication (35, 36). Mosher and Strauss (37, 38) were interested with the suffering person and recovery from debilitating episodes while others worked directly with consumers to study the value of self help (39).

Alliance with the Mental Health Law Project/ the Bazelon Center

Perhaps the most continuous and philosophically compatible relation between consumers/ survivors and professionals has been with Protection and Advocacy lawyers at the Mental Health Law Project (renamed in 1993 The Bazelon Center for Mental Health Law) in Washington, D. C. This project was founded in 1972 to promote the rights of persons with psychiatric disabilities and to take on individual and class action suits for historic impact. Its lawyers not only promoted the right to receive treatment, but—in keeping with ex-patients' demands—the right to refuse it (40). In 1980, many of its lawyers with consumer advocates founded the National Association for Rights Protection and Advocacy. It convenes yearly at meetings many consumer/survivor activists consider to be the most vital to attend (41).

Relations with Mental Health Associations (MHA)

The national Mental Health Association has also advocated for the rights of psychiatric patients. In the past, it sought accountability from providers and access to, rather than protection from, psychiatric services (42). Some associations have developed productive relationships with major consumers groups and the MHA National Consumer Supporter Technical Assistance Center was one of five centers targeted for termination by the Bush Administration in 2002.

Comment

The breadth of relationships that consumer/ survivors have established with various mental health professionals has extended their ideologies and influence in a number of research, service and policy arenas. They have gained both the ear of researchers, agency directors, and clinicians and have received funding to support some of their initiatives. It remains to be seen whether and how much these contacts and influences can help them oppose competing political pressures.

II. EXTERNAL OBSTACLES TO DEVELOPING CONSUMER RUN SERVICES

Late in 1987 the CSP, out of interest in exploring the rehabilitative potential of self help, by and for primary consumers requested state applications for 3-year Mental Health Services Demonstration projects run by and for consumers (43). The projects were intended to “implement and evaluate local services” and to demonstrate their effectiveness, which was very loosely defined. The drafters of the proposal viewed the project as ambitious and “risky” with a cost of \$3.5 million (43, p.7) , but hoped it would encourage state and local mental health agencies to keep funding self help programs as an essential component of their community support systems.

This section reports findings from two phases of study based on these projects. Phase One, conducted in 1993, concerns the period of federal CSP funding from 1988-1991 and ways in which external interferences compromised the quality of the projects and their evaluations. Phase two, conducted in 1996, concerns the demonstration projects during the subsequent four years.

Phase One: the 13 CSP Demonstration Services Research Projects, 1988- 1992

Seven of the thirteen funded projects proposed to develop drop in centers -- consumer-run programs that offered places where consumers could go to socialize, gain information and participate in advocacy or self-help activities. Two intended to start businesses; two, a state consumer office; one, a clubhouse; another, a volunteer food distribution service for the homeless.

Methodology.

In 1992, I conducted a study for CSP examining the ways in which consumers were involved in evaluating their demonstration projects (30). To learn about these processes, I conducted extensive ethnographic (44 - 46) telephone interviews with 56 people. These included 3 federal mental health officers and at least one each consumer, state officer and evaluator at every site; we also discussed the extent, nature and changes in consumer involvement on the projects. I also relied on government and related documents and archival materials.

Findings.

After the projects began, and increasingly throughout, CSP increased its expectations for the evaluations (30, pp. 29-30) without increasing budgets to accomplish them. This compromised consumers' involvements in evaluating the projects and the quality of the evaluations themselves. It also limited the staff's ability to successfully conduct both the project and evaluation, making it difficult to judge the effectiveness of the projects.

The changes were brought on by Congressional pressure on NIMH staff by lobbyists who demanded that NIMH justify its spending by requiring more rigorous evaluations. CSP staff in turn pressured the projects to include strong outcome evaluations, preferably within a standardized protocol. This change in expectations occurred despite the fact that the projects had not been funded as research demonstration grants, which traditionally demand stronger evaluations, but as demonstration services grants, where rigorous evaluations have been less important (47); indeed the very grant guidelines from NIMH considered the evaluations as secondary to demonstrating the ability to develop new services (48).

Difficulties resulting from changed evaluation expectations. The new demands created difficulties in implementing and interpreting the evaluations. Most of the projects had neither designed nor budgeted for a rigorous evaluation and had trouble securing evaluators for the new project on brief notice and limited funding. This compromised the quality of both the programs and the evaluations, and delayed starting the evaluations. It also resulted in losing the formative data that most evaluators considered more valuable and relevant than outcome evaluations at this stage of studying self help (31). Several project directors were forced to use program staff to help evaluators collect data, diverting them from working on the project.

The changed demands created several theoretical and methodological problems. Using standard evaluations to assess outcomes seemed premature in projects still trying to determine meaningful outcomes. It also did not make sense to evaluate the projects as if they were already established programs. Such standardized approaches make it impossible to detect particular characteristics that distinguish developing programs from well established ones. Several evaluators questioned using standard evaluations to compare widely varying projects. Evaluators felt that comparing formative process evaluation data among projects would have been particularly valuable to learn how organizational and managerial difficulties were resolved and whether and how state program officers were productively involved after projects were funded. Evaluators also regretted not examining the project's plans for continuity after CSP funding ended.

Suspicion Of Orchestrated Failure.

One evaluator observed how using standardized evaluations for nonstandard projects assured failure: "...so long as demonstration program evaluations are conceived as scaled down versions of 'real' research efforts and predetermined client or member outcome measures are taken as indicators of success, they cannot be" (49).

The directors of the consumer projects were concerned that the evaluations would seem weak given their late start, inadequate budgeting, and the premature mandated standard evaluation format. They also feared that the weak evaluations that would likely result would make it difficult to secure continued future funding. They were right on both counts. Passages from a report from the Inspector General's Office (DHHS 1993)

corroborated their fear: "...many respondents agree that, notwithstanding NIMH efforts to strengthen it, evaluation has been weak" (50, p.9).

This led to a premature perception of failure which diverted attention from the strengths of the projects. One state officer commented that his state's project, "was not successful in terms of the goals identified at the beginning, but from the viewpoint of empowering people, there is no doubt it was successful; I've never seen such success." Success was evident in the confidence that enabled participants to return to school, to gain significant employment, and to move on with their lives. The standardized evaluations imposed on the projects were simply unable to capture these accomplishments. If the criteria for rigorous evaluative designs had been requested from the start, the more seasoned researchers and project directors would have budgeted for them. They suspected that the changes were imposed deliberately to ensure poor results and end future funding of consumer projects. An outside evaluator observed, "It wasn't set up to succeed" (31, p. 30).

The Source of Pressure for Rigorous Evaluations. The CSP officials who pressured for more rigorous evaluations were not trained researchers and most likely did not recognize the implications of their demands. It is unlikely that they, as champions of self help, would have tried to sabotage their own efforts. Indeed, years later, they lauded the projects for having demonstrated "increased social supports, decreased use of inpatient care, and improved self confidence and decision making skills" (24, p.6).

The pressure on the projects did not come from within NIMH, but from powerful actors who were lobbying Congress. CSP staff suggested that NAMI, with its powerful lobby and strict agenda on funding biomedical research (31), was agitating for rigor. E. Fuller Torrey, a psychiatrist whose strict biomedical perspectives NAMI embraced, had also been lobbying against consumer projects that promoted social and experiential healing. After the demonstration projects ended, he wrote an angry letter to the director of NIMH stating his intention to inform Congress and the public of the way NIMH had been wasting taxpayers' money on such "fatuous" projects.

Phase II: The Fate Of The Demonstration Projects After Managed Care

In 1996, 4 years after the termination of the demonstration services projects, I investigated how they had fared since federal funding had ended. Since this was a period of restructuring of behavioral health services under managed care (51, p.4), I also wanted to learn about consumers' experiences with managed care and their expectations of how it might promote their interests.

Method: Working from my original contact list, I succeed in contacting roughly half of the original consumer leaders and state officers, and added new persons who had joined the projects or state offices. I interviewed thirty-three people: two CSP officers; six previous and three new state mental health officers; seven consumers involved with the original projects plus twelve additional consumers; one evaluator; and two non-consumer board members. Again I conducted open-ended phone interviews, this time exploring funding issues, continuity and changes in the projects, the natural course of earlier difficulties, and experiences and expectations about managed care.

Findings: As it turned out, projects could have benefited from process evaluations. Projects that had experienced organizational and managerial difficulties continued to struggle in Phase 2 and were more vulnerable to demise. Five projects lost funding and two more were on the brink of losing it. Three that lost funding reemerged with different missions, but they were still run by consumers; the other two had come under non-consumer control. Because of NIMH's interference, most of the projects lacked the formative data needed to help them move beyond their organizational and managerial difficulties, evaluate the way in which state mental health authorities should be involved, and determine their future goals or funding plans.

Funding Difficulties. Over half (7 out of 13) of the original projects could not secure funding to carry out their missions. Of the remaining six, one other came under non-consumer control. The other five have all struggled to remain economically viable. Many consumer program directors felt they were expected to work longer and harder than those in the traditional service sectors without equivalent pay or benefits. Many projects depended

on volunteers to keep going, and part time staff were paid low wages so they could retain government disability benefits. Long hours and low pay have forced even some of the most dedicated veterans to leave consumer positions. Others have transferred to jobs in the traditional mental health sector so they could receive health care benefits. Economic threats to consumer projects have varied with political administration and climate, substantiating early concerns of activists (6) and raising questions about the further impact of managed care.

Organizational and Managerial Difficulties. As novel entities, the original demonstration projects were run by consumer staff with varying levels of managerial experience, exposure to the ideology of the consumer movement, and experiences with the mental health system. These shaped their particular understandings of the meaning of consumer empowerment and control. Consumer directors with more hierarchical management styles (53, 54, 2) often pleased the local mental health officer, but annoyed consumers with strong democratic governance values (27). The interpretation of consumer empowerment and control by others, such as board members and mental health officers, also led to philosophical and organizational conflicts. In the best cases, these were worked out by the time of Phase II; in the worst cases, they compounded fiscal difficulties and impeded project success. Boards who over-managed created ongoing conflict with the staff. Other boards neglected legitimate complaints from users and tolerated managerial abuses. Both proved fatal to two projects. The insights offered by formative evaluation data might have deterred this outcome.

Involvement of State Mental Health Officers. The application for the original demonstration grants clearly specified that “responsibility, control and decision-making” be carried out by consumers (55, p. 6), but that states must provide staff to implement proposed activities (55, p. 15). How this was to be accomplished was left up to the state. Differences in the capabilities and experiences of consumer directors created varying needs for support from the state mental health office, from only filtering funding to the project to offering considerable oversight.

Inexperienced consumers, inadequate state oversight and mentoring, and the consumer and CSP “hands off” policy were fatal to some projects. Overburdened state officials found it easier to assume control rather than spend the time to mentor project staff. A “hands off” approach worked well with competent directors, but failed with novice staff who mismanaged finances, abused their power (56, 57) or didn’t request needed help (58, p. 33). One state mental health official admitted “...creating opportunities for peoplebut not mentoring them (emphasis, mine) -- it's blown up in our face.” He noted that they would hire inexperienced people, but then not hold them accountable. The lack of oversight led to lowered expectations of accountability for consumer projects, which unfairly tainted well managed consumer programs in subsequent competitions for funding. Formative evaluation data could have informed these projects, and possibly saved them.

Despite these difficulties, by the year of this study, over 35 states directly funded at least one consumer project (52, p. 160). Perceptions of unique gains from consumer programs, as noted by one state officer, outweighed obstacles, stimulated in part by external political interference. Nevertheless, the political interference from outside opponents has continued.

The next article (Part II) in this two article series will examine the impact on consumer gains in the United States of the restructuring of behavioral health under managed care. It will also consider more fully the oppositional forces attempting to erode those gains as well as the implications of the New Freedom Commission on Mental Health for the future of consumer services.

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“Recovering” Consumers and a Broken Mental Health System in the United States: Ongoing Challenges for Consumers / Survivors and the New Freedom Commission on Mental Health

Part II (of a two-part series): *Impact of Managed Care and Continuing Challenges*

by

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1. The centers targeted for cuts include the National Empowerment Center (NEC) in Lawrence, MA; the National Mental Health Consumers' Self-Help Clearinghouse, Philadelphia; the Consumer Organization and Networking technical Assistance Center (CONTAC) in Charleston, W VA; The National Consumer Supporter Technical Assistance Center at NAMI, Arlington, VA; and the National Consumer Support Technical Assistance Center of the National Mental Health Association (NMHA) in Alexandria, VA.

Abstract

This article is the second in a two-part series that examines multiple forces that have situated the psychiatric consumer movement today, either propelling it or trying to reverse its achievements in shaping the production of mental health services. Since its anti-psychiatry beginnings, the consumer/survivor movement has succeeded in promoting its self-help recovery perspectives and gaining legal rights for patients. On July 22, 2003, the U. S. President's Freedom Commission on Mental Health advocated a consumer-driven and recovery-oriented mental health system -- a major coup for consumers/survivors. At the same time countervailing forces began blocking their efforts, challenging their accomplishments and promoting opposing agendas. This article examines the impact on consumer initiatives resulting from a restructuring of behavioral health services in the United States under managed care. It also considers the oppositional economic, political and economic forces that have attempted to erode consumer gains in recent years. Last, it examines recommendations of the Freedom Commission, and considers their implications for the future production of mental health services in a political environment where consumers/survivors have recently lost legal ground.

This is the second of a two-article series that examines various forces that have situated the psychiatric consumer movement today, supporting and helping to promote its ideas or working to oppose it and to reverse its achievements in shaping the direction of mental health services in the United States. Part I of this series examined how professionals came to embrace consumer/ survivor perspectives as well as the attempts of oppositional forces to delegitimize its early gains. This part of the series will consider the impact that the restructuring of behavioral health services under managed care in the United States has had on the gains achieved by the consumer movement. It will also review continuing attempts of oppositional forces to erode consumer gains. Finally, it will examine the recommendations of the Freedom Commission on Mental Health Services and consider their implications for the future production of consumer and other mental health services. The recovery emphasis of the recommendations is of particular interest in light of adverse legal decisions that have recently impacted consumers/ survivors under the current political environment.

EMERGENT CONSUMER-DRIVEN PLANS WITH THE RESTRUCTURING OF PUBLIC BEHAVIORAL HEALTH SERVICES UNDER MANAGED CARE.

Since 1965, Medicaid has been a joint program between the federal and state governments to provide fee-for-service health care to the indigent. As states faced rising Medicaid (1) and mental health costs (2), shrinking budgets and increasingly fragmented services (3), they began turning to private sector capitated payments (4, p. 17) and managed care models to contain Medicaid expenditures for their behavioral health services. By the mid-1990s, as they were shifting from fee-for-service, many privatized their services by turning to a for-profit managed behavioral care organization. Instead of reimbursing providers directly, the states contract out services to the private managed care organization that arranges service coverage. To use Medicaid in this innovative way, states needed to obtain Medicaid waivers in order not to violate the federal government's requirement for fee-for-service arrangements (2). By now, most states have arrangements with managed behavioral care companies (5), although some have chosen either at the state or local level to manage the care themselves through a non-profit managed care vehicle.

The Lesser of Two Evils?: Consumer Hopes for Managed Care.

For many consumers from Phase Two of my study, described in Part I of this two-part series, the potential limitations of a managed care approach paled when contrasted with the problems of a mental health system they viewed as invasive, coercive and intransigent. Under managed care, they anticipated more consumer choice and provider accountability, and hoped this would shift the power balance from provider to consumer. Also, as control shifts from providers to those interested in the bottom line, consumers expected reforms might lead to reductions in involuntary commitments and less intrusive services that one activist called, "less expensive and less offensive to us." The biggest advantage many saw to managed care, however, was its absence of the "ideological baggage" of the traditional health system.

Because the potential for mental health reform is financially driven, consumers saw in managed care restructuring an opportunity to radically revise the system through their own input (6, p. 210). Many believed that the shift in power away from providers would force the system to change its standard practices. They felt that managed care provided a means of dismantling and radically transforming a mental health system that, despite their years of advocacy, has been recalcitrant to change. With the bottom line -- a different evil -- now dictating delivery of service, consumers overall felt cautious, but more hopeful than they had in the past.

Contrasts Between Managed Care and Consumer Philosophies.

Nonetheless, there are fundamental differences between managed care and consumer ideologies and approaches. The emphasis of consumer organizations on ongoing mutual support as central to recovery contrasts sharply with for-profit managed care organizations' emphasis on measurable symptom decline (7, p.

14). Managed care organizations favor time-limited standardized models that target concrete behavioral symptoms rather than ongoing community services or programs that address global subjective and interpersonal needs (8). They prefer ‘technologies’ (6, p. 228), which like a pill, help manage concrete behavioral symptoms as "natural" objects, alienated from their social and historical circumstances. Like reductive biomedical approaches, they try to eliminate the sign (the symptom or behavior) rather than improving the subjective experience associated with that sign or the social conditions productive of it (9, pp. 61-74; 10, p. 75). These technologies are consistent with the alienated and discrete service unit approach of managed care. While some technologies engage consumers in behavioral "self-change" assignments under the directions of a therapist, (6, pp. 224, 228-229), their demand for "client compliance" (6, p. 227) contradicts consumer ideals of self-determination and empowerment (11, pp. 341). Ongoing social support to help the person recover, may be too ambitious and unprofitable for managed care to consider.

Consumer Losses Under Managed Care

As for-profit managers took control of financial expenditures in behavioral health care (12, p. 233), drastic cutbacks eliminated services to persons in deep need (13, p. 110). Consistent with the philosophical aspects I outlined above, managed care has limited services only to those deemed “medically necessary” (14) and excluded continuous residential and rehabilitation treatments (15). Persons not committed involuntarily were denied hospitalization, thus enabling access only by force, not choice. Even more alarming, “noncompliant” patients were disenrolled (16, p. 35) and others with heavy service needs were pressured to disenroll by being denied services (17, p. 163). Most plans also failed to meaningfully involve consumers and their families in planning, implementation and oversight (18, p. 18).

A market driven model designed for the private sector compromises government’s responsibility to a vulnerable population in the public sector (16, p. 34). Given their primary obligation to the bottom line, for-profit managed care systems “lack a social commitment” (18, p. 9). Their cost-savings techniques of gate-keeping and utilization review were developed for a private sector where less than 10% of the populations use mental health services. Four to five times as many persons in the public sector than the private sector have psychiatric diagnoses and their problems are more severe (16, p. 165). Applying a model developed to restrict services to the less needy on a seriously needy indigent population is misguided (17, pp.164-5) and raises ethical questions (13, 19).

Backlash and the Turn to Consumerism. A backlash has developed against managed health care out of growing outrage of its failure to deliver on its promises (18, p.7) and its placing its own priorities above the public good (20, p. 2625). Under managed care, fragmentation and existing inequities are only reconfigured (21, p. 85) or widened (22). In the public behavioral health sector, where restrictive practices have endangered the very lives of the indigent population, the outrage is apparent among providers (23), family consumer groups (24), and researchers (25) alike.

Consumer Gains: Three Case Studies Of Model Service Plans

Consumers have benefited from the excesses of managed care and the backlash against it. This has led to their heightened involvement in planning and oversight of state behavioral health services (26, p. 292; 27, pp. 883-5), providers’ requests for training in their perspectives (28) and entire service delivery plans based on their idea of recovery.

Case One:

Georgia’s Certified Peer Specialists: Rehabilitation Counselors And System Change Agents. Since 1999 the Georgia Division of Mental Health under a managed care reconfiguration has promoted peer support and recovery in its public behavioral health care provisions (29). It developed the certified consumer peer

specialist (CPS) role as a core rehabilitation service billable under Medicaid. Georgia placed muscle behind this approach by requiring this service as a prerequisite for reimbursing other community treatments. Peer specialists serve as deliberate change agents to help alter how clinicians and administrators think about mental illness and recovery and help them “buy in” to a consumer-centric philosophy” (29).

Case Two:

Working the Managed Care System to Promote Recovery in Colorado. In Colorado in 1996 the director of a new partnership between a managed behavioral health care company and eight community mental health centers hoped to integrate the principles of recovery (30) and self help into routine care. She chose psychiatric rehabilitation (31) as the tool (32, pp. 25-6) and brought in a consumer leader to implement these principles. By 2001, eight drop in centers and over 18 self help groups were in service. This was accomplished by drastically cutting costly services -- like outpatient commitment and mandatory partial hospitalization, that consumers deemed infantilizing (32), and using the saved dollars to implement changes.

The shift to a recovery-based system of care faced objections from providers. By providing training in psychiatric rehabilitation that reinforced the principles of self help and recovery, many providers became open to the approach. After seeing their clients improve clinically while gaining confidence, many came to adopt the approach. Staff who refused to accept the new philosophy and treatment approach -- even at upper levels -- were terminated.

Ironically the capitation of services (where a set number of dollars follow a client, independent of particular services delivered) in a managed care model provided incentives to adopt innovative approaches (15). Prior to capitation, centers promoted services that helped maintain their financial base. Capitation and reinvestment of savings from dropped services gave them the freedom to shift dollars to support the recovery-based system. However, even more dollars would have been available with non-profits.

Case Three: A Philadelphia Self-Managed Care Plan.

In 1997 Philadelphia County created its own non-profit managed care organization, Community Behavioral Health (CBH), which contracted directly with providers. Sensitive to the vicissitudes of political change that could lead to shifts in available services, the new behavioral health system was designed to promote stability and innovation (33, p. 87) to survive shifts in political administrations. The program was guided by an unwavering “people-first” philosophy and vision of managed care to promote access to services in the least restrictive setting. The program encourages consumer choice in services, including consumer-run programs (33, p.88) and accountability by providers and administrators to those served (33, p.90). The service system emphasizes a person’s recovery through full participation in treatment and rehabilitation (33, p. 103).

As the new managed care organization expanded from a team of six to 200 employees, the original team tried to safeguard their vision and promote a sense of community and shared purpose (33, pp. 94-5). They also established a Consumer Satisfaction Team (34) consisting of pairs of consumers and family members to oversee service provision. The team made unannounced visits to treatment sites, conducted over 10,000 interviews with recipients of services. This feedback was used to redesign programs according to stated preferences from consumers.

This new system design, devoted to serving consumers themselves, grew out of fervent beliefs by progressive mental health commissioner and strong consumer and family advocates for a consumer-driven system of integrated care. The managed care approach enabled coordination and continuity of care, albeit in a

constrained budget that demanded some difficult choices. With information about consumer wants directing the program, and satisfaction and accountability built into a recovery-oriented system, this design provided a convincing model for programs elsewhere.

THREATS TO CONSUMER GAINS

Such dramatic restructuring of behavioral health systems, sensitive to consumer preferences and built on a philosophy of recovery and self-determination, marked a coup for consumers in the mental health system. By December 1999 the Surgeon General's report on mental health identified consumers as "the critical stakeholders and valued resources in the policy process" (35; 36). Through the continued labors of consumer/survivor activists and their advocates, the ideals of recovery, self-reliance and empowerment -- as opposed to chronicity, dependence and disenfranchisement -- appeared accessible. Consumers have been partnering productively with mental health professionals and researchers for two decades to promote their own understandings about the kinds of approaches and services they find most beneficial. The Surgeon General sanctioned the "new recovery approach" as being "supported by evidence on rehabilitation and treatment as well as by the personal experiences of consumers" (36). The recent Consumer Issues Subcommittee report of President Bush's New Freedom Commission on Mental Health also calls for a National Recovery Initiative for a "recovery-based continuum of community care" (37).

In the midst of these successes however well-positioned forces have been acting to limit the consumer voice, oppose their civil rights, and censor or ridicule their ideas and those of their supporters. These forces are apparent in the activities of psychiatrist E. Fuller Torrey -- an earlier opponent of the original demonstration projects, upcoming conservative psychiatrist Sally Satel, and some extremist leaders at the National Alliance for the Mentally Ill and the NAMI-California.

This section draws on considerable material from consumer websites and related links because they are a primary means for communicating and urging action among consumers and they provide an active and continuously updated source of information.

Efforts to Terminate Funding National Consumer Technical Assistance Centers that provide information on self-help, advocacy, services and policies and promote consumer's relationships with professionals. This surprise announcement came shortly before the funding date (38) after funding had been allocated and approved (39). Although Congress ultimately funded the centers, their future remain insecure.

Pressure to close the centers came from three sources -- E. Fuller Torrey, Sally Satel, and individuals in NAMI, bolstered by their pharmaceutical supporters. Torrey has been a long-time critic of the Center for Mental Health Services for supporting "anti psychiatric groups and those opposed to assisted treatment" (40) -- a euphemism for "forced treatment" through involuntary outpatient commitment. He specifically objects to funding the National Empowerment Center in Lawrence, MA for supporting "the salaries of anti-psychiatry radicals" who reject the medical model of mental illness and hold out "a false hope" of recovery without medications (41).

Satel, a psychiatrist and fellow at the conservative corporate think tank, the American Enterprise Institute, sees these consumer information centers as promoting the work of anti-psychiatry consumer-survivor groups (42, pp. 48, 61). She argues that governments should stop funding them -- something that can be "reversed overnight" (42, p. 231; 43) - and has placed herself in positions to make this happen. As a chief mental health policy advisor to the Bush administration, she now sits on the influential CMHS National Advisory Council, which holds decision making power over grants. While admitting that funding to consumer centers is modest, she worries that "it is leveraged fairly effectively" (43) and wants to stop its influence.

Andrew Sperling, NAMI's Public Policy Director, also lobbied against funding the consumer centers. According to consumer advocacy organization Support Coalition International, (SCI) (44), Sterling admitted to "inadvertently" issuing a statement on the organization's public website that he was lobbying the Bush administration to "terminate federal funding" for certain "psychiatric survivor organizations" (45). Groups that were viewed as actively challenging the "scientific basis for mental illness and its treatment" were selected. (Interestingly, The National Consumer Supporter Technical Assistance Center at NAMI was among them.) In a letter to the SCI, Sperling clarified that the policy did not come from the NAMI board, but "reflects long-standing concern regarding the activities of several "consumer/ survivor" organizations that are funded by the federal CMHS to serve as National Technical Assistance Centers" (44).

The statement was released during a four month interim period between executive directors when Eli Lilly executive Jerry Radke was placed in charge. Radke had also been on loan from Lilly earlier, as part of NAMI's "strategic planning," according to Laurie Flynn, NAMI's outgoing executive director. Eli Lilly paid his salary and also contributed \$2.87 million to the organization between 1996 and 1999 - about ¼ of the income it was receiving from the pharmaceutical industry (46). These moneys fund NAMI's Campaign to End Discrimination (47). (See below.)

Pushing for Forced Treatment (PACT and Involuntary Outpatient Commitment)

Consumers assert that the \$11+ million dollars from this Campaign to End Discrimination funded NAMI's Program of Assertive Community Treatment (PACT) (47). PACT is an outreach program that provides 24 hours/ day, 7 days/ week mobile treatment and support in the community. When PACT was first introduced in Wisconsin over twenty years ago, some consumers and their families appreciated the caring oversight of familiar staff (48); other consumers were so oppressed by it that their only refuge was to cross the state border to "escape." For many consumers today, it conjures up "a kind of mental health police force" (49). Members of a treatment team visit consumers in their home to secure their "medication compliance" by injection or watching them swallow their pills (47). The potential for abuse in shifting from "aggressive" to "coercive" treatment has concerned some mental health professionals (50), as do the profits to pharmaceutical companies that promote coercive models.

Moreover, as a treatment modality, PACT is enforceable by outpatient commitment laws. These laws order court mandated treatment requiring a person "to take the medication needed to control the symptoms" (51, p. 337) or risk inpatient commitment. In 1997, NAMI founded the Treatment Advocacy Center to promote coercive treatment and involuntary commitment; it has succeeded in implementing outpatient commitment laws in at least forty states. Under E. Fuller Torrey, its president, has won many tough battles, most recently in California.

Censoring or Ridiculing Opposing Ideas

Torrey and his advocacy group have gained success by sensationalizing and exaggerating the incidence of violence that occurs among unmedicated persons with psychiatric symptoms. Torrey has publicly disseminated an unsubstantiated statistic from a Justice Department study (52) claiming 1000 homicides are committed yearly by mentally ill people. He used the statistic again in a special issue on "Mental Illness and the Law" of *The Journal of the NAMI California* (53). Dan Weisburd, former editor and publisher of *The Journal*, investigated and questioned Torrey's statistic in his "Publisher's Note," adding that Torrey admitted it was a "guesstimate" (54). Torrey has been quoted in *The New York Times*, *the Wall Street Journal*, *The Washington Post*, *Sixty Minutes*, and in the *Congressional Record*, all of which depended on his expertise. Weisburd objected to Torrey's falsely raising public fears ostensibly for political reasons.

Members of the NAMI California Board of Directors, some of whom were close allies of Torrey, were outraged at Weisburd's comments and paid to have pages of *The Journal* containing his Publisher's Note glued shut before reaching the readership. They then terminated *The Journal*, ending its eleven years of operation.

Weisburd was censored because he threatened their ultimately successful political fear campaign to enact an outpatient commitment law in California.

The intolerance this group showed for opposing views can be seen in Torrey and Satel. as well. In 1991 Torrey wrote an angry letter to Alan Leshner, the Acting Director of NIMH, denigrating it for “fuzzy thinking” and its “absurd” support of consumer projects that questioned the medical model. More recently, he excoriated CMHS as an agency that “pursues its hippie philosophy and obstructs reform efforts” (40) adding, “among most professionals, it is ridiculed ... and widely regarded as more dysfunctional than the individuals it is supposed to serve.”

Satel, on her first day on the CMHS Advisory Council, complained that too much time had been devoted to listening to the views of a consumer -- “ ‘Patient’ is the term I prefer. Maybe that’s what the Council wants, but it’s not what I want” (55). She minimized the value of the person’s comments as a user of psychiatric services. Satel then changed the label of “consumer” to “patient,” reaffirming both disease and dependence, and challenging the power reversals consumers had worked for over decades of advocacy (42, pp. 46-7).

Satel considers the idea of social determination of illness as “one of the most pernicious themes in PC medicine” (42, p. 14), claiming preference instead for “personal responsibility and self-care.” This is ironic given her hostility to a consumer movement which is based on these very principles. Satel confines personal responsibility, however, to a person’s accepting the biomedical model of disease and complying with the doctor’s orders. Her notion does not address the complex social, political, and economic environment to in which power inequalities and their denial contribute to the production of illness, nor allows for critical self-reflection and action to address social determinants.

DISCUSSION: IMPLICATIONS OF THE FREEDOM COMMISSION REPORT IN LIGHT OF OPPOSING POLITICAL AND IDEOLOGICAL VIEWS

The New Freedom Commission On Mental Health And The Call For Recovery in Transforming Mental Health Systems

In its Interim Report to the President, the Freedom Commission on Mental Health states, “the mental health delivery system is fragmented and in disarray... (56, Executive Summary, p. 4). The final report (July 22, 2003) recommends, “fundamentally transforming how mental health care is delivered in America...” (56, Executive Summary, p. 5). Based on testimony from consumers, mental health professionals and family members, the Commission concludes that “recovery from mental illness is now a real possibility” and recommends switching from a system which “simply manages symptoms and accepts long-term disability” (56, Cover Letter) to a “consumer-centered, recovery-oriented” one (56, Executive Summary, p. 11). The Commission declares that consumers be significantly involved in everything from planning to choosing providers to delivering services (56, Executive Summary, p. 13). Further, following the 1999 *Olmstead v. L.C.* decision of the United States Supreme Court, the report encourages that services be made available in “communities rather than in institutions” (56, Executive Summary, p. 12).

Variation in Etiology, Treatment and Recovery.

The Surgeon General’s 1999 Report on Mental Health (36) identifies the immensely varied etiologies of behavioral disturbance such that “one single factor in isolation -- biological, psychological, or social -- weighs heavily or hardly at all...” (36, Chapter 2). Similarly, the Commission report acknowledges the great variation that occurs in the most promising blends of services and supports for different persons over the life course (56, Executive Summary). Thus the Commission did not provide any singular “model plan,” like the Assertive Community Treatment (ACT) which NAMI considers “the answer” for everyone, but individualized plans built on identified needs and wants of each person. ACT is just one of many possible evidence-based practices (EBP) currently available (56). At the same time, the report also includes potentially beneficial (57) emerging

best practices, which, like the consumer demonstration projects, did not have the advantage of adequate research study.

Like etiology and treatment, recovery and variation in consumers' experiences of it gained high profile in the Surgeon General and Commission reports. The concept of recovery originated with ex-patients (58), was elaborated by others (59, 60, 61, 62), and was developed by researchers (30, 31). The possibility of recovery was revisited by researchers whose longitudinal studies challenged the belief that serious mental disorders were inevitably chronic (63, 64). While recovery for survivors like psychiatrist Daniel Fisher (41) means a final cure, for most persons, it means a satisfying, socially productive life -- with or without symptoms (65, 30). Restoration of functioning or terminating psychotropic medication are not needed for recovery (60). It can be achieved without professional help (30) as it differs from professionally directed rehabilitation (36); the latter, though may help to promote it. And since recovery restores a person's dignity and self-worth, it appeals to consumers and families advocates alike (66).

Contradictory Forces: Forced Treatment or Recovery?

Where a person lies on the protection (forced treatment)/ freedom (voluntary recovery) continuum depends in large part on that person's experiences with both mental illness and the mental health system. Some consumers retain the feeling of indignity from forced treatment even if they acknowledge that it benefited them (62). Others find the loss of self-esteem it imposed so injurious that they totally reject any kind of force (58). Still others are convinced that forced treatment saved their life (42, p. 20). Some family members demand forced treatment, others find it objectionable (67) while others blame it for having lost their relative's trust. Not all NAMI members support its official policies or methods (68). They are split, e.g., on the issue of forced treatment, as in California where five former presidents of NAMI-California wrote a public letter urging members to not join extremists who were using violence to push for forced treatment (69). The danger of extremists like Torrey, Satel, and some NAMI leaders is that they use the public's fear of a misrepresented violence, and present their own views as those of a unified membership and the most advanced state of knowledge, when they are neither. The Commission in fact recommends an educational campaign to challenge the incorrect perception that mentally ill persons are more violent than the general population (56, Consumer Issues Subcommittee Report).

Conclusion

The Freedom Commission holds out hope that consumers can rebuild the mental health system so it can work for them; this far exceeds expectations of those I interviewed in my studies. In the coming months Charles Currie, a member of the Commission and the Administrator of SAMHSA, will be reviewing the final Commission report and offering an action plan. It is here where political pressures will be applied. The progressive minded Commissioners who drafted the report will face the test of reality as concrete measures to enact it are developed. Contradictory forces have never been greater. Although consumers have gained ideological ground with their recovery vision, opposing forces have made strides in gaining coercive treatment programs and outpatient commitment laws. These same forces tried to end federal funding of major consumer centers, censored corrective reporting that threatened their agenda, and earlier interfered with the demonstration projects. These forces are backed by drug and corporate money, have well-funded lobbyists and gain easy access to the President.

In contrast, consumer organizations have always been economically disadvantaged. Without the ability to draw dues from a poor consumer base and the lack of (and disinterest in) support from drug companies, they must depend on government funding and remain vulnerable to political whim, as was seen with the five technical assistance centers. Still, their leaders have developed relationships with government and mental health professionals and have convinced them of the fundamental value of the recovery perspective.

But the battle is not over. The Commission's report -- and recovery vision -- will not appeal to everyone. Many, however, like the current NAMI President, support a recovery-oriented approach (70). As a continuous process, recovery will not be achieved through the time-limited interventions that managed care organizations find profitable. It is also not likely to be achieved through the timely taking of medication in the absence of a meaningful and productive life. It is even less likely to be gained through forcing treatment on someone. Recovery is a holistic, if elusive, concept that incorporates multiple physical, social, economic, political, and even spiritual dimensions (71) that may vary from person to person and over time. To the extent that recovery might impede the interests of some groups (e.g., managed care organizations, the pharmacological industry, psychiatry even families) they are likely to challenge it as a principle for restructuring mental health services. Already Marcia Goin, president of the American Psychiatric Association, reserves comment on it, citing instead a biomedically based model (72). Torrey called it harmful for sending a "cruel message" to very impaired people (73); still he asserts that as a distant goal, it is "laudable." And Satel -- whose appointment to the CMHS Advisory Council was approved by Currie -- will be in a position to pass judgment on action plans based on it.

The Commission's report was crafted by some progressive individuals, including Dan Fisher, whose Technical Assistance center was one of five targeted for closure. Sally Satel's power to pass judgment on recommendations Fisher helped construct may seem defeating. However, it may be that recovery, because of its focus on individual transformation, will be a palatable idea. For as Littlewood argues, America is a "psychologized society," which interprets "social power as personal performance, argues for autonomy and self-scrutiny, for consumer choice and therapeutic transformation" (22, pp. 174-5). Thus as long as recovery is focused on transforming the self rather than the system, and as long as it does not directly threaten the biomedical/ pharmaceutical industries, it is likely to be viewed as innocuous, if not desirable. Recovery and the community support on which it depends may also seem compatible with the Bush Administration's engagement of voluntary organizations. Indeed the psychiatric consumer self-help movement started precisely this way.

Thus recovery may be a timely idea around which both the left and right may rally. As a seemingly innocent, non-threatening concept, it may gain adequate political support despite some protests from Torrey, Satel and like-minded groups. Moreover, with outpatient commitment laws now in place in most states, any lingering concerns extremists may hold about recovery are likely to be attenuated. Still, recovery and self-help may be less innocent than they seem. By forcing people to examine their lives, their illnesses, and their possible etiologies, a recovery-based system will demand that they closely confront the societal conditions of their existence. To achieve genuine recovery, they will have to address not only their biological vulnerabilities, but also present and past sources of possible oppression -- social (e.g., sexual, gender, racial, familial), political, and economic -- and eventually confront these. Herein lies its transformative potential.

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Hegel's Dialectic and Reflective Practice

A Short Essay

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Abstract

Cotton describes current reflective practice in nursing as an essentially disempowering and devaluing experience. Gilbert draws on a Foucauldian framework to argue that reflective practice imposes a degree of surveillance on healthcare professionals and refers to Johns' (1995) model of guided reflection as one of the postmodern 'technologies of power'. This paper will attempt to provide a brief critique of Johns' model from a broad Hegelian perspective. Central to Johns' idea of reflective practice is the goal of accessing, understanding and learning through lived experience. It is this that enables the practitioner to take "congruent action towards developing increased effectiveness within the context of what is understood as desirable practice." Johns' model offers, I believe, a robust guide for reflective practice. It enables the practitioner to analyse an experience by promoting the cognition of the contradictory parts that come together to make up that experience.

Introduction

For the postmodern philosophers Michel Foucault, Jean Baudrillard and Jean-François Lyotard, there is little relationship between thought and reality (Rees 1998, p.295-297). Each exists in separate compartments. The recurring danger in human history is that people should come to believe that their ideas can result in a better world (Lyotard 1989, p.8-9). However, within nursing, postmodernism has been celebrated as a liberating philosophy that enables the practitioner to take responsibility for his or her actions (Stevenson 2001).

The 'hegemonic discourse' of reflective practice in nursing has been challenged from a postmodern perspective by such writers as Cotton (2001) and Gilbert (2001). Calling for "new conceptualisations" of reflection and whilst citing little empirical evidence, Cotton describes current reflective practice in nursing as an essentially disempowering and devaluing experience. Gilbert draws on a Foucauldian framework to argue that reflective practice imposes a degree of surveillance on healthcare professionals and refers to Johns' (1995) model of guided reflection as one of the postmodern 'technologies of power'. This paper will attempt to provide a brief critique of Johns' model from a broad Hegelian perspective.

The Hegelian dialectic and Johns' model of reflection

G. W. F. Hegel (1770 – 1831) described how contradiction lies at the root of all change (Miller 1969, online). His theories have been developed and enriched to explain the course of social change throughout history

(Marx and Engels 1967, p.79; Marx 1976, p.102-103). This dialectical approach suggests that change and movement are inevitable and inherent in all living things. Whilst a detailed discussion of Hegelian dialectics is beyond the scope of this paper, it should be noted that totality, change and mediation are underlying themes in Hegel's writings. These themes can provide an antidote to the reductionism of the empirical method so common in contemporary nursing theory. Rees describes how "any two elements in contradiction cannot be dissolved into one another but only overcome by the creation of a synthesis that is not reducible to either of its constituent elements" (Rees 1998, p.7).

In contrast to empiricism, reflective practice suggests that when a structured and analytical methodology is used to reflect on experience, new knowledge and theory can be generated (White, 1997). In the empiricist system, the part is seen as a pre-existing unit with little relationship to others. Parts may superficially affect each other but not change their fundamental nature. Reality is analysed using static concepts and individuals are held to be the building blocks of social theory. Thus, this methodology lends itself well to the neoliberal economics of present day health service reform. In a dialectical system, the relationship of the parts to each other and thus to the whole is fundamental (Rees 1998, p.5). Not only is the whole more than a sum of its parts, but the part becomes more than it is individually by being part of the whole.

Central to Johns' idea of reflective practice is the goal of accessing, understanding and learning through lived experience. It is this that enables the practitioner to take "congruent action towards developing increased effectiveness within the context of what is understood as desirable practice." Appendix A provides Johns' framework for applying Carper's four patterns of knowing. This enables the practitioner to interpret his or her experience within the empirical, ethical, personal and aesthetic spheres of knowledge (Carper 1978, cited in Johns 1995). Here, the empirical and aesthetic ways of knowing stand in contradistinction to each other. In Hegelian terminology, they form a unity of opposites. Both are discrete whilst simultaneously processing the ability to interpenetrate. The two patterns of knowing exist as parts of a totality, presented as they are as components of Johns' model. Johns makes the important point that empirical knowledge is transcended by the process of assimilation into the practitioners personal knowledge and thus into practice.

When describing the relationship between the four ways of knowing, Johns states that the aesthetic emerges as the dominant sphere and is informed by the empirical, personal and ethical dimensions. In this way, the aesthetic mediates the other areas of knowledge. The result is a synthesis that enables the practitioner to respond to new situations with a changed perspective. The model facilitates the process of self-awareness, description, critical analysis, synthesis and evaluation identified by Atkins and Murphy (1993). Within Johns' system, the contradictions between the practitioner's actual and desirable practice are significant as they can provide a powerful motivational force for change. The practitioner may be in a state of "cognitive dissonance" (Festinger 1957, cited in Clark 1999) that can be overcome by the use of Johns' model.

Criticisms of the model

Heath (1998) points to the complexity and diversity of practice in the real world. She suggests that practitioners need considerable expertise and reflective skill when using Johns' model so as not to see the examination and categorization of their knowledge as a mere "academic exercise." Echoing the postmodernists' concerns, she refers to a degree of controversy surrounding the excessive use of structure in reflection. Similarly, Kitchen (1999) states that any model of reflection should not be over prescriptive. Johns' model is described as useful in one-to-one supervised reflection but is considered somewhat restrictive, especially for experienced practitioners. In general, practitioners need to guard against the dangers of reducing experiences to a series of questions without any real reflection.

Conclusion

Johns' model offers, I believe, a robust guide for reflective practice. It enables the practitioner to analyse an experience by promoting the cognition of the contradictory parts that come together to make up that

experience. This method bares striking similarities to Hegel's philosophical approach and is considered to be the very essence of the materialist dialectic (Lenin 1972, p.359). Over time, this process enables the practitioner to avoid the assumptions that might otherwise be made if based on a purely empirical understanding of reality. Given that a reductive process is needed to fit the practitioners experiences into one of Carper's four categories, some of the criticism above is understandable. However, these concerns entirely miss the point. By treating knowledge as a rich totality, the use of Carper's four patterns of knowing enables the full examination of practice, theory and assumptions and thus enables the individual to develop as a reflective practitioner.

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Assessing Coping in Schizophrenia

A Rationally Devised Scoring Scheme to Assess Coping in Schizophrenia: Internal Consistency and Associations with Work Performance

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Abstract

Most assessments of coping behavior were not developed for the unique needs of persons with schizophrenia. Accordingly, a rationally derived scoring scheme for six aspects of coping implicated in psychosocial function in schizophrenia was constructed using the items of an existent instrument: the Ways of Coping. The revised scales demonstrated higher levels of internal consistency than the original scales across two schizophrenia samples ($n=53$, $n=48$). Coping strategies identified using the revised scales were predictive of work performance over a two-month period, while no relationship was found between coping and work function using the original scheme. Implications for research are discussed.

Introduction

Persons with schizophrenia often report chronic difficulty coping effectively with both major and minor stresses (Corrigan, & Toomey, 1995; Frese, 1993; Mueser et al., 1997). They may possess a relatively limited repertoire of coping strategies (Rollins et al., 1999) and tend to avoid rather than actively attempt to solve problems (Farhall & Gehrke, 1997; Lysaker et al., 2003b; Wilder-Willis, et al., 2002). As a matter of coping style they thus may spend relatively little time thinking or talking about how to resolve a dilemma, and/or be less likely to actively and constructively respond to the stressor. Beyond being intuitively a matter of concern, maladaptive coping patterns in schizophrenia are of larger importance because they have been linked to symptom exacerbation and failure to sustain community tenure (e.g.; Hultman, Wieselgren, & Oehman, 1997; Macdonald et al., 1998; Meyer, 2001; Middleboe & Mortensen, 1997; Takei et al., 1990; Tarrrier et al., 1988; Wiedl, 1992).

While the significance of coping deficits in schizophrenia is widely recognized, less is understood about how to measure adaptive coping in schizophrenia, how to detect when key aspects of adaptive coping are absent and how to systematically determine the individualized needs of persons who would benefit from acquiring better coping skills as part of their rehabilitation. One reason for this is that most coping inventories have generally been designed to measure coping among persons in the community with medical but not major psychiatric conditions (Dropkin, 2001; Siegel, Gluhoski, & Karus, 1997) and may, therefore, be less sensitive to the pervasive and possibly idiosyncratic deficits found in schizophrenia. Literature ranging from Bleuler (1911/1950) to contemporary accounts (Carter & Flesher, 1995) suggests that some with schizophrenia may have relatively unique difficulties coping. They may for instance fail to cope adequately because they contemplate action but do not act or because they act decisively but without adequate contemplation. Other authors have pointed out that some with schizophrenia may either consciously choose to not act upon or merely ignore the presence stressors, both due to a lack of any meaningful sense of personal agency (Hoffman et al., 2000; Lysaker et al., 2001; Lysaker et al., in press; Ventura et al., 1999, Young & Ensign, 1999).

In the current study we have, therefore, set out to determine whether the items of an existing coping scale, the Ways of Coping Questionnaire (WCQ, Folkman & Lazarus, 1988) could be scored in a different manner in order to assess the unique difficulties in schizophrenia that might be linked to functional impairments. While this particular instrument has been established as a measure of coping in a community-residing well population, the factor structure of the scale, as with other scales, does not appear to accurately reflect coping behaviors used by individuals with chronic illness (Wineman, Durand, & McCulloch, 1994), which may also be the case for individuals with schizophrenia. We chose the WCQ as a starting point, rather than attempt to invent another instrument, because the WCQ contains multiple items that are face valid for schizophrenia, several of which are not employed in the present scoring instructions. Additionally persons with schizophrenia have been found to validly complete the WCQ and, though perhaps flawed, the profile resulting from the existing scoring scheme has been linked to symptoms and personality in schizophrenia (Lysaker et al., 2003a).

In attempting to create a new scoring method for the WCQ we sought to assign each WCQ item to one of six coping categories, determined a priori based on the literature reviewed above. The first two categories were “considering” which refers to thinking or talking with others about what to do, and “acting,” which refers to

taking direct action in regard to a stressor. As suggested by Monti, Abrams, Kadden, & Coney (1989; pg. 83), effective problem solving first requires resisting the temptation to either respond with an initial impulse or to do nothing at all, and then after considering the situation a solution is devised and acted upon. Since either of these elements of problem solving (considering and acting) might be impaired in schizophrenia we reasoned that each should be measured separately. The third category was “ignoring,” which refers to a preference for attempting to put the stressor out of one’s mind, or choosing to “not think” about the stressor. The fourth was “resigning” and that refers to a choice to not act because there is nothing to be done. The fifth category was “positively reappraising.” This dimension is virtually identical in name and description to one of the original 8 categories of the WCQ and refers to the tendency to see “the silver lining,” in a stressor, or to recast a negative stressor in a positive light. The final dimension was “self-soothing.” When this coping strategy predominates, the person’s primary concern is focused on how to regain emotional equilibrium by reducing overwhelming feelings of anxiety or negative affects rather than constructively dealing with the stressor itself.

In the current paper we present the item assignments created according to the new scoring scheme and then compare internal consistency and predictive validity of the revised and original scoring systems. In particular we predicted that if the new scheme were more sensitive to coping deficits in schizophrenia, it would demonstrate an average higher coefficient alpha than the original scale across at least two samples. We secondly predicted that a preference for considering and acting, the two subscales we hypothesize contain essential elements of successful problem solving (Monti, et al., 1989) would prospectively predict better psychosocial function in a work program. In other words, we reasoned that if the new scoring system validly assessed preference for considering and acting when faced with stressors, than participants with a preference for both should be better problem solvers and fare better over time in a work program over time.

Materials and Methods

Participants

Participants were collected from two independent samples: the first was used for the initial comparison of internal consistency between the original and our revised scoring scheme. Informed written consent was obtained for both samples and both studies received full approval from the appropriate hospital and university research review boards. Sample 1 was composed of 51 male and two female participants with a SCID (SCID-I; Spitzer, et al., 1994) confirmed diagnosis of schizophrenia ($n = 39$) or schizoaffective disorder ($n = 14$). All were recruited from the outpatient psychiatry clinic of a VA Medical Center for a larger study of the correlates of obsessive-compulsive symptoms in schizophrenia. On average, participants were 44 years old ($SD=9$), had 13 years of education ($SD=2$), and 10 lifetime psychiatric hospitalizations ($SD=11$) with the first occurring at age 26 ($SD=6$). All participants were in a post-acute phase of illness as defined by having no hospitalizations or changes in medication or housing in the month before entering the study. Participants were excluded who had a diagnosis of mental retardation, or another neurological disorder. WCQ responses from these participants were included in a previously published study of the clinical correlates of personality in schizophrenia that used the original scoring scheme (Lysaker et al., 2003a).

The second sample was used to evaluate the stability of subscales constructed using Sample 1. Participants were recruited from the outpatient psychiatry clinic of a VA Medical Center for a larger study of the clinical effects of psychosocial rehabilitation, which provided outcome data that was later used to evaluate the external validity of the coping scales. Sample 2 was composed of 47 males and one female with a SCID (SCID-I; Spitzer, et al., 1994) confirmed diagnosis of schizophrenia ($n = 31$) or schizoaffective disorder ($n = 16$). On average, participants were 47 years old ($SD=7$), had 12 years of education ($SD=2$), and 12 lifetime psychiatric hospitalizations ($SD=13$) with the first occurring at age 24 ($SD=7$). All participants were in a

post-acute phase of illness as defined by having no hospitalizations or changes in medication or housing in the month before entering the study. Participants were excluded who had a diagnosis of mental retardation, or another neurological disorder. WCQ responses for these participants have not been used in any studies published elsewhere.

Instruments

Work Behavior Inventory (WBI; Bryson et al., 1997): is a 35 item inventory developed specifically for the purposes of assessing behavior at work for persons with severe and persistent mental illness. A trained rater completes the WBI following direct observation of participants' work behavior and an interview with the participants' supervisor. Each WBI item consists of a specific behavior which is rated as a "1" persistent problem area, "2" occasional problem area, "3" average performance, "4" an occasional area of strength, or "5" a frequent area of strength. Items are used to generate a total score, ranging from 35 to 175 possible points, that is the sum of five sub-scales: social skills, cooperativeness, work habits, work quality, and personal presentation. Data supporting the factorial and concurrent validity of the WBI have been reported elsewhere (Bryson et al., 1997). Good to excellent interrater reliability were found in this study with intraclass correlations ranging from .82 to .94. WBI scores were also found to have predictive validity in terms of subsequent vocational outcomes (Bryson et al., 1999)

Ways of Coping Questionnaire (WCQ; Folkman and Lazarus, 1988): is a self-report instrument that asks participants to recall a recent stressor and then rate how often they have used 66 different behaviors to cope with that particular stressor. Scale scores are additively derived from individual items and divided by a total score to provide relative scores for a total of 8 scales: Confrontative Coping, Accepting Responsibility, Distancing, Escape-Avoidance, Planful Problem Solving, Positive Reappraisal, Self controlling and Seeking Social. These eight scales use a total of 50 of the total 66 items available. This instrument has been used in studies of coping in schizophrenia in a variety of samples (Lysaker et al., 2003a; Lysaker et al., 2003b; Lysaker et al., in press). In order to control for response bias, as suggested by the authors, relative scores were calculated. These were obtained for all scales by dividing a scale mean by the mean total such that a score of greater than "1" reflected a greater preference for that coping strategy while a score of less than "1" reflected a lesser preference for that strategy.

Procedures

After all participants provided informed consent, diagnoses were confirmed using the SCID-I (Spitzer, et al., 1994). Participants were then administered the WCQ by a research assistant as part of a battery of two larger studies as noted above. Participants in Sample 2 were offered a paid job placement for up to 20 regularly scheduled hours per week at a VA medical center. Job duties were equivalent to entry-level positions and regular job site supervisors provided supervision. Efforts were made to match participant's interests and skills with work placements in such areas as the escort service, housekeeping, the computer laboratory, and customer service. Job placements were made without reference to WCQ scores. Work behavior was evaluated using the WBI during the first, third, fifth, and seventh week of work by trained bachelor or masters level research assistants. WBI ratings were made blind to WCQ scores. We chose to use multiple assessment of work behavior rather than single points since previous research with other samples has suggested persons with schizophrenia take several weeks to settle into a stable work pattern (e.g. Lysaker et al., 1993).

Results

To derive the rational scales, two raters (PL & RL) separately sorted each of the 66 WCQ items. This yielded an agreement rate of over 90% and the remaining 7 items were sorted according to a consensus between raters. The final solution using the original item numbers was thus: Considering: items # 2,8,18,22,31,42,45,48, 60,63,64; Acting: items # 1,5,6,7,20,25,26,34, 39,46,49,52,62; Ignoring: items # 4,10,13,16,21, 24,32,35,40,41,50,59; Resigning: items # 9,11, 12, 29,43,51,53,55,58,61; Positive reappraisal:

items #15,23,27,30,36, 38,65; and Self-soothing: items # 3,14,17,19,28,33, 37,44,47, 54, 56,57, 66. Correlations of the original scales with the new scoring scheme are presented in Table 1.

Table 1 Intercorrelations of Original and Rationally Derived Scales Within Sample 1 (n = 53)

Original Scales	Rationally Derived Scales					
	Acting	Considering	Ignoring	Resigning	Positive Reappraisal	Self-Soothing
Confrontive Coping	.586***	.299*	-.423**	-.406**	-.107	.128
Distancing	-.377**	-.393**	.597***	.088	.035	.162
Self-Controlling	-.275*	-.349*	.279*	.385**	-.237	.224
Social Support	-.238	.798***	-.202	-.006	-.051	-.316*
Accepting Responsibility	-.150	-.115	-.104	.280*	-.061	.128
Escape-Avoidance	-.440**	-.308*	.529***	.624***	-.500***	.054
Planful Problem Solving	.644***	-.236	-.238	-.338*	.189	-.152
Positive Reappraisal	.170	.081	-.297*	-.553***	.736***	-.121

*p<.05; **p<.01; *** p<.0001 ^aCorrelations are based on relative scores calculated for each subject.

In order to examine the reliability of the new scoring scheme relative to the original scheme, we assessed the internal consistency of each version of the WQC scale across two independent samples by calculating coefficient alpha for each rational and original scale. Item analysis was conducted at the scale level to identify improvement in internal consistency that could be gained through the removal of select items. A single item (#65) assigned to the Positive Reappraisal scale appeared to detract from the overall coefficient alpha and was therefore dropped from the scale. Maximum inter-item correlations were achieved under the proposed scoring scheme for all other scales. As depicted in Table 2, higher coefficient alphas were consistently observed within both samples at total scale and individual subscale levels for the rational scoring scheme. Total scale reliability for the rational scales was considered adequate to good, with coefficient alpha values averaging .79 and .80 in Sample 1 and Sample 2 respectively. In contrast, the mean coefficient alphas for the original scoring scheme were lower on average for both samples, with four of the eight subscales failing to produce acceptable reliability (below .70) when evaluated independently.

Table 2: Internal Consistency

Lysaker Scales	Sample 1 (n = 53)	Sample 2 (n = 48)
Acting	Alpha = .86	Alpha = .87
Considering	Alpha = .82	Alpha = .83
Ignoring	Alpha = .75	Alpha = .74
Resigning	Alpha = .74	Alpha = .75
Positive Reappraisal	Alpha = .81	Alpha = .84
Self Soothing	Alpha = .77	Alpha = .74
Scale Average	Alpha = .79	Alpha = .80

Original Scales

Confrontive Coping	Alpha = .74	Alpha = .72
Distancing	Alpha = .65	Alpha = .65
Self-controlling	Alpha = .60	Alpha = .61
Seeking Social Support	Alpha = .82	Alpha = .85
Accepting Responsibility	Alpha = .66	Alpha = .53
Escape-Avoidance	Alpha = .67	Alpha = .73
Planful Problem Solving	Alpha = .83	Alpha = .77
Positive Reappraisal	Alpha = .80	Alpha = .82
Scale Average	Alpha = .72	Alpha = .71

To examine how preference for the methods of coping involved in successful problem solving impact work performance, participants from Sample 2 who had worked for at least 6 of the first 7 weeks (n=34) were divided into two groups. The first (n = 10) group, the “Considering - Acting” group, was composed of participants with relative scores of greater than “1” on both the “Considering” and “Acting” scales (i.e. participants with a preference for both of the elements essential to problem solving, but which are often impaired in schizophrenia). The second group (n = 24), labeled “Other”, was composed of participants with a relative score of 1 or less on either or both of the “Considering” or “Acting” scales. Thus members of this group could have a preference for only one or neither of those scales. Repeated measures ANOVA was then conducted comparing the WBI Total scores across weeks 1, 3, 5 and 7 for the Considering-Acting group and the Other group. As illustrated in Figure 1, the Considering-Acting group had significantly higher WBI total scores ($F = 5.798, p < .05$). There was also a significant time effect with both groups improving over time ($F = 10.260, p < .01$) but no interaction ($F = 1.22, p = .28$). Post-hoc analyses comparing the individual WBI subscales are reported in Table 3.

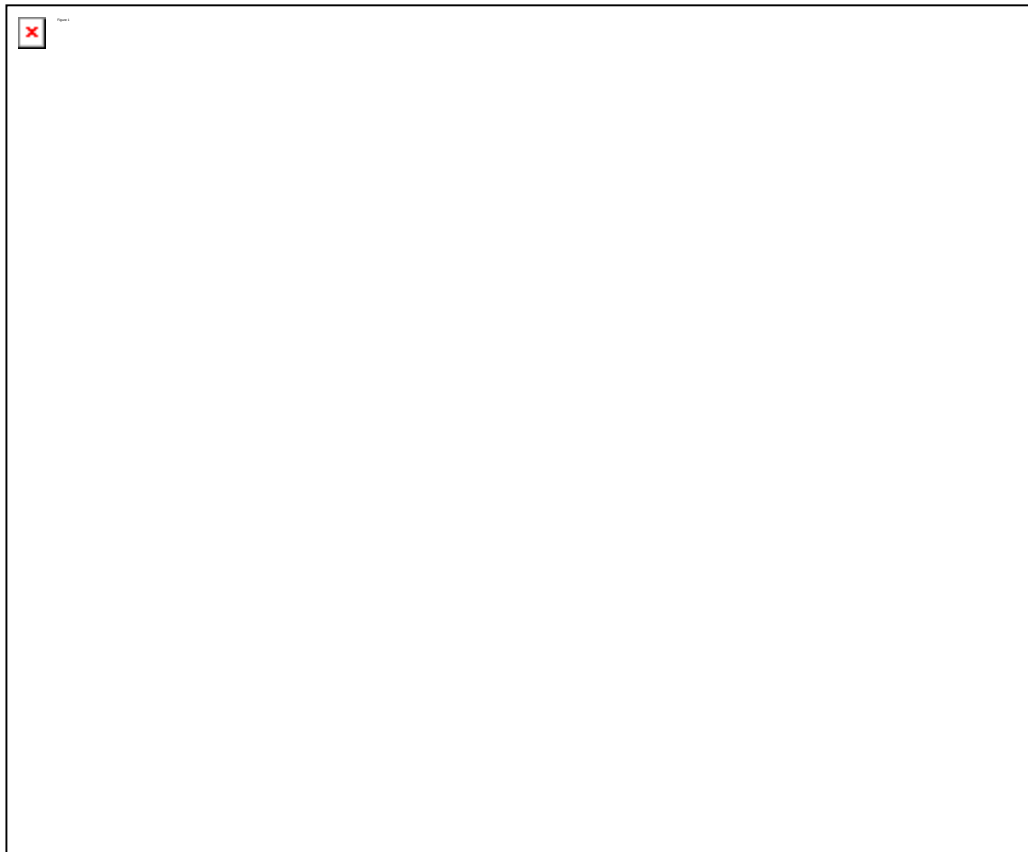


Figure 1 - Participants identified as “Considering-Acting” (n = 10) and “Other” (n = 24) based on relative preference for rationally derived coping strategies. Repeated-measures ANOVA across weeks 1, 3, 5 and 7 of work indicated significantly higher WBI total scores ($F = 5.798, p < .05$) associated with preference for “Considering-Acting”.

Table 3: Repeated Measures ANOVA of WBI Scores Across 7 Weeks of Work

WBI Scale	Consider-Act (n = 10)	Other (n = 24) Effect	Time Effect	Group
	Mean (SD)	Mean (SD)		
Social Skills			F = 12.33***	F = 3.31 (ns)
Week 1	22.79 (2.20)	21.91 (2.08)		
Week 3	24.19 (2.81)	22.02 (3.03)		
Week 5	24.35 (3.18)	23.08 (2.65)		
Week 7	25.04 (3.36)	22.79 (2.65)		
Cooperativeness			F = 6.62*	F = 7.24**
Week 1	23.90 (2.68)	22.70 (2.13)		
Week 3	25.19 (2.44)	23.58 (2.24)		
Week 5	26.15 (2.79)	24.10 (3.87)		
Week 7	27.21 (3.29)	22.98 (3.48)		

Work Habits			F = 3.84 (ns)	F = 3.56 (ns)
Week 1	23.39 (2.83)	21.11 (2.68)		
Week 3	24.01 (2.82)	22.53 (3.85)		
Week 5	24.85 (3.77)	23.05 (4.59)		
Week 7	25.71 (4.42)	22.09 (4.78)		
Work Quality			F = 7.40**	F = 4.59*
Week 1	23.09 (3.07)	20.45 (2.73)		
Week 3	24.72 (2.47)	21.79 (3.19)		
Week 5	24.82 (4.40)	23.08 (4.56)		
Week 7	25.40 (4.99)	22.82 (4.34)		
Personal Presentation			F = 10.58**	F = 5.02*
Week 1	22.60 (1.95)	21.54 (1.38)		
Week 3	23.49 (3.45)	21.81 (2.31)		
Week 5	24.04 (3.28)	22.16 (2.67)		
Week 7	25.19 (3.25)	22.25 (3.14)		
WBI Total			F = 10.26**	F = 5.80 *
Week 1	115.78 (2.95)	107.74 (1.90)		
Week 3	121.56 (4.09)	110.92 (2.64)		
Week 5	124.18 (4.99)	115.47 (3.22)		
Week 7	128.56 (5.34)	112.88 (3.44)		

* p<.05; ** p<.01; *** p<.0001

Given the correlations between Considering and Seeking Social Support and between Acting and Planful Problem Solving, as well as roughly equivalent levels of internal consistency between these four scale, we next examined whether participants with preferences for both Planful Problem Solving and Social Support Seeking (n = 10) had better work performance when compared to individuals who use only one or neither of these strategies (n = 24). These analyses failed to find significant differences on the WBI (F = 1.0, p = .30). Of note, the Considering-Acting group and the Planful Problem Solving-Social Support Seeking group were dissimilar with respect to membership, sharing only 7 out of 13 participants in common (54%).

To determine whether a simple preference for Considering (n = 13) or Acting (n = 17) from our revised scale prospectively predicted work performance, we conducted two repeated measures ANOVA comparing the WBI total scores. Neither of these analyses produced significant differences: F = 1.94, p = .17, F = 1.33, p = .26, respectively. Lastly, an exploratory analysis was conducted to determine whether preference for Planful Problem Solving (n = 23) or Social Support Seeking (n = 17), according to the original scales, could independently predict better work performance. Again, neither was found to produce significant differences: F = .027, p = .871 and F = .370, p = .548 respectively.

Discussion

In this study a rationally derived scoring scheme was created which reorganized the items of the WOC into six primary according to deficits commonly reported in schizophrenia. Of these scales, five tapped aspects of coping conceptually distinct from the intent of the original scales, and one was virtually identical. Correlations among these scoring schemes suggested that the newly created scale scores were related to the original scores but far from identical. When compared across two samples, the rationally devised scales had better internal consistency than the original scales overall, with several of the original scales but none of the new scales failing to achieve acceptable internal consistency. When used to predict work performance, it was concluded that persons who expressed a relative preference for both acting and thinking prior to starting work achieved

consistently better work performance over a period of two months in a work program than individuals who demonstrated preference for either of these two methods independently or, conversely, neither. As might be expected, ad hoc analyses showed that persons who utilized coping strategies involving both acting and thinking performed better at work, particularly in areas of instrumental function relating to work performance and cooperativeness. In addition, personal presentation and sociability were found to be areas of strength for these individuals relative to coworkers. Of note, these findings could not be replicated using a combined preference for the original planful problem solving and social support seeking scales of the WCQ, or when either was present alone.

Taken together these results support the further investigation of a scoring scheme rationally tailored for the study of coping in schizophrenia. The rationally derived conceptualization presented herein appears to provide more reliable and valid assessments of the coping strengths and deficits in schizophrenia, and thus may represent an incremental improvement from the original scoring scheme. With replication, these methods may have practical application as well. In particular, vocational programs may be able to identify persons at risk for poorer outcome on the basis of their coping preferences, and eventually develop or employ interventions aimed at helping these individuals to become more willing and comfortable in using more thoughtful and action-oriented coping strategies.

Of note, there are limitations to this study. Generalization of findings is limited by sample composition. Participants were generally middle-aged males involved in treatment. It may be that a different relationship exists between coping and function among females, younger men with schizophrenia, persons declining treatment or others in different stages of illness. Clearly more research is necessary with broader samples. We also measured coping once as it was reported in response to single recent incident. Future studies may wish to include longitudinal assessments of coping and more qualitative information regarding a broader range of situations with which individuals cope, as it may be that these relationships vary depending upon the stressor and its context. Furthermore, while statistically meaningful, differences in work performance were modest and it cannot be ruled out that the relationships between coping and work performance were not mediated by other factors. Replication is necessary with studies designed to control for mediating variables before these findings are used for the basis of intervention. Lastly, assessment of the predictive validity focused on relative preference for acting and considering and the other scales were not examined directly. Future investigation is needed to further validate the remainder of the proposed rational scales.

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Psychotherapy Treatment of Torture Survivors

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Abstract

This article presents a project about applying a model of brief therapy to the rehabilitation of survivors of torture and organised political violence. The model includes both narrative and body oriented therapeutic approaches to the treatment of trauma. The narrative approach focuses on the construction of meaning in the traumatic events and in so doing makes it possible for the client to view his life story from different angles. The body oriented therapeutic approach includes a range of techniques that can help the client to control his bodily reactions to the trauma. In addition, the article contains an evaluation of the brief therapy project, exposing the tendencies of the treatment effectiveness. The tendencies are that despite the fact that the treatment did not notably reduce the symptom experienced by the clients, many had, due to the treatment found new and better ways of dealing with their pain. Also, since the treatment aimed at strengthening the client's abilities to cope with the complexities of his/her problems on a daily basis, many experienced an increased sense of manageability and meaningfulness in regards to daily life.

Introduction

Recent studies of refugees seeking asylum in Western countries have showed consistently higher rates of mental distress in the refugee population compared to those found in the general population. The symptoms include depression, anxiety, demoralisation, stress, fear pain, and PTSD (Silove & Steel, 1998; Edvall-Dahlgren et al., 1989). The potential for trauma is present at various stages of the refugees' experiences such as during the flight

from the country of origin, and during the reception procedure in the host country (Packness, 1998, Monaldi & Strummielo, 2001). In addition, several studies show that many refugees suffer from experiences of torture, political violence and various other forms of physical abuse in addition to their migration experiences. These horrifying memories of the past interfere with their concentration, causing them to be anxious and withdrawn (Silove, 1999; Silove, Ekblad & Mollica, 2000). Inevitably, the increasing numbers of survivors of torture and political violence presenting to asylum services in Western countries pose significant challenges for the mental health services in these countries, calling for the development of new methods and intervention strategies to the rehabilitation of torture survivors.

Literature Review

Torture survivors are assisted either by stopping torture, i.e., primary prevention, or by the provision of torture rehabilitation services, i.e., secondary and tertiary prevention. Amnesty International has adopted the simplest, most broad definition of torture: “*Torture is the systematic and deliberate infliction of acute pain by one person on another, or on a third person, in order to accomplish the purpose of the former against the will of the latter*” (A.I., 1973).

In 1984, the United Nations, in the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, adopted the following definition:

“For the purpose of this Convention, the term ‘torture means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purpose as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed, or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by, or at the instigation of, or with the consent or acquiescence of, a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in, or incidental to lawful sanctions” (UN, 1984).

This definition was restricted to apply only to nations and to government sponsored torture. It did not include cases of countries where torture such as mutilation or whipping is practiced as lawful punishment, nor did it include cases of torture practised by gangs or hate groups.

In 1986, the WHO working group introduced the concept of Organized Violence, which was defined as:

“The inter-human infliction of significant, avoidable pain and suffering by an organized group according to a declared or implied strategy and/or system of ideas and attitudes. It comprises any violent action that is unacceptable by general human standards, and relates to the victims’ feelings. Organized violence includes “torture, cruel inhuman or degrading treatment or punishment” as in Article 5 of the United Nations Universal Declaration of Human Rights (1984). Imprisonment without trial, mock executions, hostage-taking, or any other form of violent deprivation of liberty, also fall under the heading of organized violence” (WHO, 1986; Van Geuns, 1987).

Torture is a perverted form of human interaction, which involves at least two persons, the victim and the torturer. It is characterised by extreme degradation, humiliation and dehumanisation as the torturer inflicts severe physical or psychological suffering on the victim. The torturer/victim relationship is characterised by its anonymity and is highly asymmetric in that the situation creates a relationship of extreme dependency, permitting the psychological manipulation of the victim (Doerr, 1992). Thus the victim is trapped in a double bind situation because he either has to co-operate with the torturer, by giving confidential information or he has to suffer more pain and possible death (Lira, 1990).

Torture is a technique with the purpose of carrying pain almost to the infinite. Michel Foucault writes: “*Torture is the art of maintaining life in pain, by subdividing it into a thousand deaths, by achieving before life ceases the most exquisite agonies*” (Foucault, 1979).

At an individual level, torture has been used as punishment with the purpose of destroying the victim as a human being through the systematic infliction of severe pain and psychological suffering. Also, torture has been used to destroy the victim's identity by forcing him to become a traitor to his comrades and to his ideology. At a social level, authoritarian governments of all colours have used torture as a political tool to create fear and intimidate dissident groups with the purpose of preventing the population from expressing opposition towards government policies. Thus, countries subjected to a climate of terror may contain whole communities affected by violence. In order for such societies to engage in processes of reconciliation and national healing, the social reparation needs to go through the sequential steps of truth, compensation, justice and pardon (Padilla and Comas-Diaz, 1987; Becker, 1990; Bronkhorst, 1995; Quiroga & Gurr, 1998).

In 1997, Amnesty International reported torture and maltreatment in 115 out of 215 countries (53,5%). The prevalence of torture in selected samples of refugees varies from 5 - 70% depending on the composition of the sample in relation to nationality, sex, age, and point in time (Lavik, 1996). The prevalence in samples of unselected refugees showed intermediate values. For instance, a random sample of 3000 asylum seekers who arrived to Denmark in 1986 showed a torture prevalence of 20% (Jepsen, 1988), while a prevalence of 23% was found by a Swedish group of Red Cross in a sample of refugees requesting asylum in Sweden (Horvath-Lindberg, 1988). In the last 10 years, the medical and psychological service programs for survivors of political or other forms of organised violence have expanded enormously. While Amnesty International identified 100 programs in 25 countries (A.I., 1997), the IRCT listed 94 programs in 49 countries, belonging to its network of torture rehabilitation services (IRCT, 1997) and further estimated that as many as 166 programs were existing in 81 countries in 1997 (IRCT, 1998).

Torture methods have been divided into physical and psychological methods. The Chilean Human Rights Commission listed 85 different types of physical torture (Orellana, 1989). Physical torture can be brutal with severe physical damage and a high lethal rate (Vazquez, 1977), but often the torturers want to avoid visible body marks. The most frequent methods of physical torture are beatings, suspension, stretching, electric torture, submersion, suffocation, burns, cuts and sexual assaults. The time between the exposure to torture and the medical examination is crucial; the closer the victim is examined to the time of torture, the easier it is to observe any physical signs (Quiroga & Gurr, 1998).

In contrary to the physical effects of torture, the psychological symptoms are much more persistent, as torture is intended to damage the person's self esteem and destroy the person's trust in fellow humans. The psychological methods of torture are mostly tailor-made and will often include induced exhaustion and debility through food, water and sleep deprivation, isolation of the victims, monopolisation of perception for example through movement restriction and high pitch sounds. In some cases, the victims and their families are threatened with death or they experience sham executions. In other cases the victims witness the torture of another prisoner or of family members (Quiroga & Gurr, 1998).

There are similarities between emerging psychological symptoms in torture survivors and the main constellation of symptoms corresponding to those collected in the syndrome labelled as Post Traumatic Stress Disorder (Cunningham & Cunningham, 1997). However, labelling torture survivors as having PTSD is much too inadequate a description of the complexity and magnitude of the effects of torture (Reeler, 1994; Becker, 1995; Lira, 1998). A widespread theme in the testimonies given by survivors of genocide and organised violence is that many experience the feeling of having survived their own death; a symptom similarly described in relation to holocaust survivors.

The diagnosis DESNOS (Disorder of Extreme Stress not otherwise specified) includes several of the symptoms found in torture survivors and varies from PTSD by emphasising the torture survivor's changed perception of the self, advantageously leaving the DESNOS diagnosis to describe survivors of long-term suppression and totalitarian control (Herman, 1992).

Many torture survivors develop symptoms of major depressions, obsessive compulsive disorders and psychoses, and there is a significant level of sexual dysfunctioning whether or not the person was subjected to sexual torture. Numerous studies have showed that many torture survivors experience changes in their identity (Somnier & Genefke, 1986; Barudy, 1989) and have a high level of comorbidity (e.g. Cunningham & Cunningham, 1997, Somnier et al., 1992). The torture survivor may have lost body parts, which means the loss of normal bodily function. Also, they may have lost family members, work, or credibility and status, because even though they resisted a breakdown during the torture, their colleagues are nevertheless likely to be suspicious of them. If the torture survivor leave the region to seek asylum, the losses can be compounded and exceed to include the breakdown of marriages and courses of education as well as deteriorations in wealth and status. Thus, torture is not only a very important life event, but also the cause of many other important life events, often leading to the loss of normal life development (Turner & Gorst-Unsworth, 1993; Skinner, 1997).

Additional research reviewed by Charney (1993) and Southwick (1994) has established a psychobiological mechanism for PTSD. This could explain the endured duration of the PTSD symptoms, and why current treatments are only partially effective, thereby having significant implications for the treatment of PTSD patients and survivors of torture.

While all the effects listed above have implication for the assessment and treatment of torture survivors, the relationship between the therapist and the survivor should also be considered. A trusting relationship must be developed in order for progress to happen. Similarly, cultural understanding is essential when choosing the methodology of the social assessment of the torture survivors, as a standard western psychiatric interview can be highly counter productive (Mollica, 1989). There are good arguments for a bio-psycho-social approach to treat and rehabilitate torture survivors, as this approach provides long-term flexible involvement to cope with relapses, thereby endorsing increased functionality for the torture survivors in order for him to achieve personal goals. As a result, increased functionality for the survivor becomes the main outcome objective for the therapy, rather than symptom reduction (Shalev et al., 1996) though that may also be a goal for treatment.

Often, the needs of the victims of organised violence are multiple and many have a combination of psychological, social, medical and legal problems, explaining why numerous programs of psychological treatment have adopted multidisciplinary approaches. Some of the treatment approaches used with torture survivors are cognitive therapy, insight therapy, psychodynamic therapy, behaviour therapy and the testimony method. It looks as if the therapists bring to the task whatever school of psychotherapy they have learnt. However, since there is little evidence in the literature saying that one approach is better than another, the effectiveness of available treatment programs remains unproven (Quiroga & Gurr, 1998). Some programs involve group treatment, and focuses on symptoms of torture-related PTSD, while other programs organise group therapy for children and adolescents within or across cultures. Overall, group therapy provides opportunities to develop trust and build social network. Also, it is very important that the treatment programs acknowledge that there are major differences between cultures in how they conceptualise the process of torture and its meaning. Consequently, indirect supportive methods may be more useful than those of pushing the survivors to talk about their experiences of torture (Mollica, 1988). Thus, cultural issues in psychotherapy indicate the need for different approaches for each culture when designing interventions (Quiroga & Gurr, 1998).

The approach of community development aims to empower a particular community, by addressing the internal and external needs of the individuals, the groups and the agencies that coexist within it (Aristotle, 1990). Various efforts have been made to train members of a community to help victims of torture and repression through small group discussions within the community. This is done in order to recognise the signs of torture and trauma, and share the traumatic experiences, thereby supporting the survivors in helpful activities (Loughry, 1990 in Hong Kong and the Philippines; Beristain, 1992 in Guatemala and El Salvador).

Whilst relaxation therapy and sensitive physical techniques can relieve some of the legacies of severe pain,

dysfunction and stress, medication also has a definite place in the therapies found to effectively help torture survivors. However, the use of medications should be modified by the ethnic differences in metabolism, nutritional status, concomitant medications and age (Quiroga & Gurr, 1998).

Despite the fact that no accessible papers or private reports give any information about the cost effectiveness of the treatment services and approaches listed above, the costs to a society of not providing therapy to torture survivors are not insignificant. Also, services of torture treatment in countries where torture has occurred or still is occurring denote that torture is wrong and that all people are valued and worthy of treatment. Thus, the services of torture treatment in countries practising torture systematically can support the people in their struggle for equal participation and democracy, thereby contributing to the overall country development. The growing interest in this new field of psychology and medicine is increasingly leading to the establishments of torture rehabilitation programs around the world (Quiroga & Gurr, 1998).

In conclusion, it is clear that in order for services to meet the needs of the consumers and thereby become sustainable in the longer term, they need to follow a range of principles. The principles are:

- Interventions should be based on the best current knowledge while also consider any cultural differences.
- Interventions must be diverse to meet the range of needs, differing in type and severity.
- Participation is essential in determining the best use of resources and in developing sustainability.
- Good governance of services, and education and training at all levels are essential for good performance.

However, efforts of providing more profound information about the interventions offered by the torture rehabilitation services in different environments are seriously impeded by the fact that most studies published about torture survival are mainly descriptive in character. The studies describe various disorders in traumatised torture survivors, such as PTSD, anxiety, pain, dissociation, somatoform and cognitive disorders, and social withdrawal but the symptoms are only assessed before therapy has taken place. Combined post traumatic stress - post traumatic growth studies of therapy are almost non existent, and the few clinical follow-up studies that exist have limitations due to the lack of definitions of diagnostic criteria and the lack of control groups (Mollica et al., 1990). In other words, in order to come up with clear and valid recommendations on the functioning of rehabilitation services, and thereby be able to answer any of the many possible questions about approaches to torture rehabilitation, studies on several areas are needed (Quiroga & Gurr, 1998).

The remainder of the article contains a presentation of a brief therapy project conducted at the Danish Red Cross. The project, which was running for a two-year period, was established because the traditional psychosocial treatment methods offered by the Red Cross Trauma Centre comprised psychiatric or psychological consultations and occasional sessions of relaxation therapy, even though this strategy proved incapable of reaching torture survivors suffering from severe symptoms of PTSD. Thus, in order to provide the torture survivors with optimal treatment the project aimed at developing new methods for rehabilitating survivors of torture. The project introduced a combination of narrative and body therapeutic approaches to the treatment of psychological trauma. The team behind the project was inspired by Levine's methods of treating chock-traumatised individuals (van der Kolk, 1996; Levine, 1997).

Brief Therapeutic Treatment of Traumatised Asylum Seekers

The Danish Red Cross Asylum Department is responsible for refugees seeking asylum in Denmark. For the most part, the refugees stay at the Red Cross asylum centres for longer periods of time until their asylum status has been decided by the Danish Government. Asylum seekers severely affected by symptoms of PTSD are referred to the Red Cross Trauma Centre where different forms of psychosocial treatment are offered. Traditionally, treatment of trauma in Denmark has been based on psychodynamic analytic theoretical frameworks, involving long-term therapies with 50-100 sessions and great exposure to the trauma as a significant part of the treatment. As an alternative, the project conducted at the Danish Red Cross asylum centre included a short-term therapeutic model, meaning that the torture survivors suffering from PTSD were offered eight sessions of treatment, each

session consisting of two hours. The model comprised a combination of psychotherapy and relaxation therapy. It was believed that the short-term therapy model could reduce the torture survivors' symptoms of PTSD and thereby enhance their quality of life, because, instead of exposing the torture survivors to their respective traumas, the short-term therapy model emphasised techniques that:

1. could give the client the possibility to regain control and distance to the traumatic experience;
2. tried to uncover as many resources as possible in the client's past;
3. reinforced the regaining of action potentials through talents/interests/abilities that are part of the client's potentials (Berliner & Wiking).

As mentioned above, the short-term therapy model included a narrative and body therapeutic approach inspired by Levine (1997), in which focus is on the psychosomatic consequences of trauma. Many torture survivors suffering from trauma either have muscular tensions or over-relaxed muscles, which indicates that the body is reacting to the trauma and is dealing with it at an unconscious level. The body's way of dealing with the trauma results in somatic grievances, which metaphorically is termed as the language of the body, or in other words, the body's way of communicating the trauma.

The following provides a brief description of the different methods and techniques used during the eight session of the brief therapy treatment. The psychologist and the relaxation therapist introduce the course of treatment by informing the client about the potential perspectives of the treatment. The psychologist explains how the treatment can be an opportunity for the client to transform some of the problems in his life. The relaxation therapist gives information about how, during the sessions, the client will learn a range of methods and techniques to alleviate his physical sufferings. Subsequently the client is asked to account for the symptoms he is experiencing. It could be that he is not able to sleep at night, that he suffers from nightmares, or that he avoids social contact. Being quick-tempered or suffering from flashbacks are also symptoms of PTSD.

The session continues as the psychologist tries to normalise of the client's symptoms by using Levine's tale about the animal from the prairie/pampas/Serengeti. The tale is about how animals, when hunted, often plays dead as part of a survival instinct. However, in contrast to human beings, the animal is able to recover from the shock immediately after it has occurred. Through these facts, the client is introduced to a narrative of a temporary *state of shock*, which can be a way to help the client to deal with his anxiety in relation to whether he is going mad or suffering from psychiatric disorders. The client is thereby offered other ways of perceiving his reactions to what has happened as well as his present state of mental health.

The second session is devoted to the establishment of *the safe place* in the client. *The safe place* is a place the client knows well and therefore is able to describe in detail. It is often closely associated with good memories and positive experiences from the client's life, such as school years, childhood, family gatherings etc. The idea behind the technique of *the safe place* is that the client can use it as a mental refuge whenever flashbacks and other repressive thoughts are troubling him. Also, *the safe place* can be used in meditation and relaxation exercises, and when the client tries to go to sleep. However, it is important to note that in some cases *the safe place* can provoke many different feelings in the client, as it can be also related to the loss of mental and physical places from the past.

In the third session, focus is on the actual symptoms that the client is experiencing, but in some cases it can be too difficult for the client to speak of his thoughts and feelings regarding the trauma. As an alternative, treatment can focus on the physical pain the client is experiencing, because the body and the physical pain are perceived to contain a narrative about the trauma. By getting the client to either talk about his current physical condition or by getting him to draw his pain, a narrative about the traumatic experiences slowly begins to emerge. Similarly, through relaxation therapeutic exercises aimed at strengthening particular areas of the body, the client's narrative about how he experienced himself in certain situations can develop into emphasising the strengths and resources existing in his (re)actions. This way of combining the relaxation techniques with more verbal or creative

treatment methods allows the client to express his problems in a different way, giving him the opportunity to bring his thoughts and feelings to surface.

Relaxation therapy is used also to raise the client's awareness of his body and to increase the muscular relaxation. By stretching and relaxing of the muscles concerned, the client can experience that the physical pain is alleviated. Also, the relaxation techniques can help the client to calm down and relax, and they can help him detect his body's resources in order to rebuild his defence-system.

The third session also includes the symbolic escape with help from the *fight and flight instinct*. This technique is conducted with the client lying on a mattress on the floor, and is about gently exposing the client to parts of the trauma. However, as the client relives the trauma from the past he is now helped to escape and to get away from the oppressors, as opposed to when the trauma actually happened.

In the fourth session, the work is focused on the traumatic experiences in the client's past, and the technique of *the safe place* is used frequently as a way for the client to control his memory. At this point, a more narrative approach is adopted, which focuses on verbally constructing the meaning of the traumatic incidence from the client's past in order for him to view his personal life-story/narrative in relation to a larger discursive framework such as religion, politics, ethics, etc. Thus the discursive framework represents a larger more meaningful narrative in the client's life. In so far, the client is religious or is affiliated with a particular ideology; chances are that it can be less problematic for the client to reconstruct the meaning of his traumatic experiences. For instance, a person who is very religious has the option of praying to his/her God in order to ask for meaning of what has happened. Similarly, myths and legends from either the client's culture or the psychologist's culture can be used to make sense of the trauma.

Whereas the fifth and the sixth session continue the work with the themes and techniques introduced in the previous sessions, the seventh and eighth session are set on the future. These sessions concern the question of how the client wishes to feel in two years. Focus is on the client's ability to use *the safe place* in order to control his bodily reactions as well as his thoughts and feelings associated with the trauma. Likewise, as the renegotiations of the trauma become manifested and the client begins to perceive his traumatic experiences and personal narrative as corresponding to a particular superior, meaningful narrative existing in his life, his capability of controlling his physical and psychological conditions is enhanced. Subsequently the treatment is directed into emphasising the socioeducative aspect of the client's life, meaning that at this point, focus becomes on improving the client's overall control of his life. This means that the client is presented with different options of how to deal with issues influencing his daily life, thereby offering him a chance to move away from the role of the victim. The socioeducative aspect of the treatment could for instance be a discussion with the client about what the advantages are of going to the library and read the newspapers in his native language, instead of staying at home, alone.

An additional way of getting the client to relate differently to his problems is to invite his significant other(s) to the session. Thereby the seventh and eighth session becomes about how the client, in co-operation with his nearest relations, can sustain the improvements achieved during the therapy, and how these improvements can be used in his daily life.

During the course of treatment, the psychologist and the relaxation therapist are aware of not creating transference or causing the client to regress to a former emotional state. Instead they aim at establishing an equal collaboration with the client. As a result of the treatment, the client gains the experience of having physical control over his body, and he experiences a sense of *wholeness* in relation to himself as an individual with a variety of strengths and resources.

The following case illustrates clearly some of the dilemmas and paradoxes pertaining to the (re)negotiation and (re)construction of the meaning of traumatic events.

Case: *The Story of the wolf (Told by the Psychologist)*

He is a young man of his best years, handsome and much civilised as he appears at the clinic. He seems a little confused as we sit down to begin the session. His attention is on a poster hanging on the wall; a picture of a mysterious house by a canal made by the artist Magritte. The picture is beautiful and harmonious, but only until you realise that it is really quite wrong: whereas the house and its reflections in the canal is dark, the sky is rather bright, transparent and blue just as in the midst of a nice summer-day. People who see the picture become fascinated and also lightly disturbed by this illusion represented in the picture, as it reveals a much darker side than visible by first impression. I think of it as a very Jungian picture, and the young man is deeply fascinated as well as disturbed as we reveal its depths together.

He tells me that he was a student at an art-school back home in Chechen, before the upcoming conflict and civil war with Russia. We work together in various settings and I follow my schedule of 'digging up' his resources and happy memories, creating and establishing his 'safe place' and so forth. Also, I tell him the legend about how animals survive shocks in nature, and I try to come up with the worst imaginably beast in his country. I ask him about an animal that hunts sheep, and he proposes the wolf as the animal most likely to hunt for sheep. However, as we continue and go through the narrative, this technique does not seem to work as it usually does. Unlike my other clients, this young man is not engaged in the exercise with the wolf as the perpetrator and the sheep as the victims. After some time he tells me that his nation has adopted the wolf as a sacred symbol of the fight for freedom and liberation. This means that he has been taught to identify himself with a wolf, which has become a symbol of partisan activity in a very rough war between poorly armed freedom fighters opposite the Russian war-machine. Regrettably, the setting is over before I am able to interpret and correct my mishap in the mythic symbols of this case.

Later, in another session, he reveals another story about himself that increasingly is disturbing and hurting him in his thought as well as in his nightmares. On two occasions, he has been captured by the Russian authorities and been subjected too hard and lengthy torture. In addition, he was forced to see a friend being eaten by wild dogs, but presently this is not really what troubles him. Rather, he is plagued by, as he puts it 'the laws of war', which forced him to torture and kill some Russian criminals, who were turned into soldiers by the Russian army, with the purpose of killing people in the Caucasus region in unscrupulously high numbers, as he describes it. At the time, he was sure that torturing and killing these criminal soldiers was the only thing to do. Alternatively, they would have gone into local villages and terrorised the population, by killing and raping children and women, young ones as well as old ones. However, he now feels that torturing and killing these men was not fully justified, and is anguished by the thought that he was rougher to these guys than was needed. He is afraid that he will have to answer to his God for his actions in this respect, because according to his God no man may take justice into his own hand, meaning that it is forbidden to take the life of another human. Thus, along the lines of his religious belief he was very wrong to kill and torture these men, and he regrets having done so and is tortured by the memories of what happened during this episode.

Here is a true dilemma to be negotiated: is there such a set of parallel laws of human life that cannot be mixed and jointly understood, but rather seem to exist in their own order and legitimacy? We approach and negotiate the dilemma in different ways. We consider the fact that we are sitting in the locations of the Red Cross in Denmark in a civil state and a civilised country, as we prefer to think of it. The laws of war as they are described in the Geneva Conventions are ratified by most countries in the world, and these rules must first and foremost be the foundation from which to consider issues of acts of war. However, we must appreciate also that the rules set by the Geneva Conventions first of all are ideals to believe in and from which to set the standards. The question is why Russian soldiers are not made to follow the rules which their government has ratified in several protocols, and why is this young man considered a war-crime perpetrator according to these protocols? He does not know how to interpret this or make an understandable synthesis of this presumably rather contradictory stuff. On the one hand, it was his indisputably duty and responsibility to discreetly exterminate the enemies of his country, but on the other hand, he can be proclaimed as a warcrime perpetrator according to the Geneva protocols. Also, his God will judge his actions as violating essential religious ethics and morale laws. So, is he in fact a hero or a perpetrator?

Through the therapy, we negotiate the dilemma and we try to make some sense of what has happened and discover its

meaning. In this respect, meaning is perceived as understanding and acceptance of some basic rules and laws of human life. This is quite difficult because in humanity as we know it, we do not really have the innermost and final answers to such dilemmas, do we? – And, we could, by good reason, doubt if we ever will reach such answers. Sometimes, it looks as if there is a genuine contradiction between the standards and the philosophy of human rights and the Geneva Conventions on one side, and the practise of war even in the so-called civilised world on the other. If not in practice then in theory we are able to recognise and consider these different, contradictory or even antagonistic laws of life, meaning that despite the fact that the young man is not fully satisfied or reassured by the outcome of our discussion, he is nevertheless very relieved at least to discuss these issues. Thus, we establish that his actions should be considered and judged by different human standards:

1. By the standard of combatants fighting against one another, he might be in his rights to follow orders, in so far that there was no situation of imprisonment of the soldiers as it is described in the Geneva protocols.
2. If there was a situation of imprisonment, he would be a possible a war-crime perpetrator.
3. According to his religion, he would have to answer to his God for his deeds and maybe suffer for it.

The discussion reminded me of how Tibetan monks and nuns were able to put up with torture in Chinese imprisonment, and I told him about how they thought of the liberation of Tibet as their foremost goal. Also, they felt that the Dalai Lama was there with them, which transformed their suffering into a religious time of trial. The Tibetan monks and nuns were even filled by sorrow for the perpetrator because, according to Buddhist belief, he would be the victim of torture in another life as a consequence of the basic laws of cause and effect.

By Buddhist human standards and philosophy my young man has been exposed to both sides of the coin in one single life, meaning he has been the victim of torture as well as the torturer. It could be argued that this represents a very instant process of cause and effect, but the question is whether this can justify his actions. Most likely not, but he is relieved by the opportunity to negotiate it this way. Even if we can not forget what has happened, we might possibly forgive others and ourselves.

Also, we talk about responsibility. As he is the father of a new-born son, he recognises that there has to be some kind of morale laws and ethical choices from which to create the standards of life.

He is still worried about his past and about how he can find meaning, moral and ethic confirmation in these patterns of the past. Nevertheless, he is now free to seek meaning by challenging the narratives and values, which he grew up with.

The Wolf it is a gruesome and violent beast, however, the wolf is also a very clever fighter and a social member of its tribe and it belongs to the same ancient source of dogs, which we hold as pets in our homes. Any course of life must be viewed from different perspectives and from different systems of values, even though it cannot always be ignored as a moral or more profoundly as a legal problem in theory and practise.

From the case, it is possible to learn that intervention and support are not only about symptom reductions, but rather that these phenomena encompass the client's psychological, physical, moral and social abilities to cope with real life problems on a daily basis. The question is therefore whether the short-term therapy model, with its narrative and body therapeutic approach, is capable of embracing such complexities of human trauma.

Evaluation of the Brief Therapy Project

The National Red Cross Psychosocial department invited MET to perform an outcome assessment of the short-term treatment program conducted with traumatised asylum seekers at the Red Cross Trauma Centre. The purpose of the evaluation of the project was to assess the methods and techniques used for treatment in the project, thereby measuring the treatment effectiveness. The evaluation had a combined trauma - resilience focus and made use of a follow-up design. In order to scrutinise the theoretical framework and thereby develop a more sufficient understanding of the treatment process, the evaluation comprised both quantitative and qualitative analyses of the data in its assessment of the effectiveness of the treatment methods.

It is important to note that the results of the evaluation are irresolute due to practical complications. Consequently, only tendencies and descriptions of the treatment effectiveness are presented here.

Even so, the evaluation revealed the importance of early systematic interventions in torture survivors suffering from severe trauma. In order to prevent the asylum seekers from deteriorating, the intervention should happen already in the pre-asylum phase. Also, the evaluation emphasised the need of a larger, controlled evaluation of the method used for treatment of torture survivors in a context of the pre-asylum phase.

As mentioned above, the objectives of the short-term therapy treatment project were to help the client to gain control and distance to the trauma, to uncover possible resources in the client's past, and to help him regain his action potentials.

The evaluation pointed to the fact that the brief therapy treatment seemed to have an effect on the general psychological modes of functioning. This did not mean that the symptoms had diminished, but rather that the clients had found new and better ways of dealing with their pain. There was a clear tendency of perceiving ones health more positively after treatment, despite the little change in how the clients perceived their quality of life. Thus, even though no change was shown in symptom reduction, it was clear that the clients during treatment had strengthened their sense of comprehensibility, manageability and meaningfulness. This included partial relief of mental and physical numbness, which were substituted by new action potentials. In addition, as the treatment progressed the clients were able to provide descriptions of the traumatic experiences, and subsequently it became possible to obtain a clear picture of what the clients had been through.

From a theoretical perspective the treatment is aimed to impact the symptoms and the resiliency factors, in which resiliency is perceived as being able to employ the resources available in the client in order to deal with present problems and symptoms. This aim is underlined by the fact that a person can be emotionally strong while simultaneously lacking the actual tools to deal with a particular situation. Evidently, this form of treatment focuses on the traumatic experiences in order to capture the nuances of strengths and weaknesses so that the client can learn to live with what has happened. Techniques such as creating *the safe place* and learning to relax make use of the different potentials inherent in the clients.

The evaluation of the brief therapy model concluded that it is possible to reach asylum seekers suffering from severe trauma through the use of these particular treatment methods. The model's combined focus on psychological, physical and social parameters made post-traumatic growth possible in the context of the traumatised asylum seeker. Further development of methods for treating asylum seekers suffering from severe trauma, should use a combination of qualitative and quantitative methods in order to focus on the combination of psychological, physical, and social problems as well as the resources present in the real context of the traumatised asylum seeking population.

Conclusion

As a response to the increasing numbers of torture survivors presenting to asylum services in Western countries, this article has presented a model of intervention strategies for the treatment and rehabilitation of survivors of torture and political violence. The brief therapy model included a combination of narrative and body therapeutic approaches to the treatment of trauma. Whereas the narrative approach about constructing meaning of the traumatic event makes it possible for the client to view his life story from different perspectives, the body therapeutic approach includes a range of techniques helping the client to control his bodily reactions to the trauma.

The case showed the significance of not only focussing on symptom reductions, as it illustrated how the intervention strategies should strengthen the client's abilities to cope with the complexities of his problems on a daily basis. The evaluation of the brief therapy model showed that even though the clients did not experience notably symptom reductions, many had found new and better ways of dealing with the pain. As the treatment related to the specific complexities present in the client's life, and subsequently focused on presenting the client

with new action potentials, the brief therapy model, with its narrative and body therapeutic approach, proved particularly effective on the clients' sense of manageability and meaningfulness in daily life.

[Footnotes](#)

[2] Participation is defined as the involvement of the target community in the creation and management of services.
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Ethical and Social Dilemmas Surrounding Community-based Rehabilitation in Costa Rica

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Abstract

The National Psychiatric Hospital in Costa Rica is the only hospital that provides healthcare services for chronically, mentally ill patients. One type of psychiatric service at the National Psychiatric Hospital that specifically aims to meet patients' biological, psychological, and social needs is community-based rehabilitation (CBR). Patients receiving rehabilitative care at the hospital are able to develop basic living and communicative skills as a healthcare team helps patients learn how to live with their mental disorders in a community outside of the hospital environment. Though CBR is beneficial to the clinical and social welfare of patients and their families, programs have not been fully developed and implemented into the community due to a lack of resources and support by the national healthcare system in Costa Rica, corresponding agencies, and community leaders. The national healthcare system, known as the Caja Costarricense de Seguro Social (CCSS), prides itself on its aim to bring healthcare to everyone within the borders of Costa Rica. However, this aim has not been realized partially due to Costa Rica's current economical problems associated with an unstable global economy; financial constraints have greatly impaired the CCSS's ability to support programs that deliver healthcare beyond the basic needs of patients. However, even those programs specifically designed for meeting the basic needs of patients such as CBR for the mentally ill are not being supported by the CCSS. Besides reasons of financial instability, the CCSS may also be hesitant in supporting CBR because of the program's unknown effectiveness in helping patients. While small-scale efforts at the National Psychiatric Hospital have been made to predict the effectiveness of CBR, it remains unclear, from ethical and social points of view, as to whether the positive effects outweigh the possible moral dangers associated with the implementation of mental health rehabilitation programs in Costa Rica.

Introduction

The focus of this paper is to explore the ethical and social dilemmas associated with the deliverance of

psychiatric care as a basic need in Costa Rica through CBR. However, before these ethical and social dilemmas are identified and examined through critical ethical analysis, I first describe the history and current status of the National Psychiatric Hospital of Costa Rica and the services it provides to patients with debilitating acute and chronic mental disorders. This research is based on interviews conducted with healthcare providers, clinical and community observations, and reflections on the ethical dilemmas surrounding community-based rehabilitation in Costa Rica. This paper concludes with recommendations on how resources should be made available to patients with mental illnesses and whether community-based rehabilitation would be a beneficial program for Costa Rica in light of some relevant ethical and social concerns.

Background: Costa Rica's National Psychiatric Hospital

The National Psychiatric Hospital of Costa Rica, known as Hospital Nacional Psiquiátrico Presbítero Manuel Antonio Chapuí, is located in Pavas, a town outside of the capital of San Jose. The Minister of Justice, Dr. Carlos Durán, founded this hospital in 1890 after noticing that many prisoners in the San Jose jails were mentally ill and should not be incarcerated with criminals. Instead of incarcerating the mentally ill, he built the National Psychiatric Hospital to provide care and treatment. The National Psychiatric Hospital was the first European-style asylum in Costa Rica, which initially housed about 325 patients (Gallegos and Montero, 1999). The number of patients entering the hospital grew exponentially throughout the 20th century and a dramatic shift from asylum-based care to hospital-based care occurred in the mid-twentieth century as professional healthcare teams began to take an interest in caring for and treating patients with mental illnesses. To provide mental healthcare services to the growing mentally ill population, the hospital was moved from downtown San Jose to Pavas (about 20 minutes outside San Jose) in 1974.

In 1975, community mental health care was integrated into the Costa Rican mental health care system with much hesitation due to the fear that community mental health would replace the mental hospital (Gallegos and Montero, 1999). In 1978 the Pan American Health Organization and World Health Organization (PAHO/WHO), along with the Colombian government, met to discuss the needs of mental healthcare, i.e., making mental healthcare accessible to all. They made recommendations for developing and implementing programs with “wide coverage, multidisciplinary teams, and coordinators” (Gallegos and Montero, 1999, p. 27). Although it was evident that there was a need for effective programs, there were several obstacles for developing and implementing such programs. Gallegos and Montero (1999, p. 27) write, “the obstacles facing Costa Rica derived from a lack of will to promote changes and an insufficient number of psychiatrists in public positions (i.e., planners and decision makers) interested in implementing change.”

In 1982, several recommendations were presented to Costa Rican health authorities for improving community mental healthcare throughout the country. Besides coordinating mental health services with the national health system, it was recommended that mental hospitals should be replaced by community facilities. Additional recommendations were made to set up a national mental health network, which addresses all levels of prevention, along with the placement of psychiatric beds in general hospitals (Gallegos and Montero, 1999). Since the 1980's psychiatric beds have been set up in general hospitals in the San Jose area, including the Children's Hospital, but these beds are for acute psychiatric patients and are centrally located in the capital area, resulting in a seriously low percentage of psychiatric beds throughout the entire country. Although there are some developments moving toward a national mental health network that addresses all levels of prevention, no such network is fully functional at this time. Also, since recommendations were made, community facilities have not yet been fully developed and implemented to improve the mental health status of patients or as a way to replace The National Psychiatric Hospital, which still remains the center of mental health services. Unfortunately, because there is only one hospital able to care for and treat both acute and chronically ill patients, this limits access to the greater population in need of mental health services. Nevertheless, the National Psychiatric Hospital has made considerable efforts to provide the best care possible given the lack of resources, e.g., medical technology, clinicians, and the support of other healthcare professionals.

Currently (2002-03) the National Psychiatric Hospital has 811 beds and in 2001 had about 3900 discharges. Of the 811 beds, 400 are used for chronically ill patients, who permanently live at the hospital and the remaining beds are used for acute patients who stay for a short period of time (the average stay is 20 days). The hospital provides care and treatment to men, women, adolescents, pediatric patients, and geriatric patients. Patients are typically received in the emergency room with an observational unit, and those patients with acute disorders are then admitted to the intensive care unit so clinicians can determine the extent of the patient's mental and/or physical condition. Although women, men, adolescents, and the elderly are separated into different areas of the hospital, the general organization of the hospital is based on the needs of patients and the level of ease in caring for these patients.

The National Psychiatric Hospital is divided into six units or wards. The first two wards, Wards 1 and 2, are used for acutely ill, easily handled patients. Wards 3 through 6 are used for patients who are difficult to manage and who require intensive rehabilitation conduct programs. Ward 5, also referred to as "transitional home", contains chronic patients who are self-sufficient and enrolled in a therapy program called "Daily Life". The "Daily Life" program teaches and guides patients in activities such as cooking, shopping, dressing and bathing. Once the patients are able to complete daily life tasks and manage their lives within the hospital they are transferred to group homes, or independent houses known as "Las casitas", which are located behind the hospital grounds. There are also public and private rehabilitation centers where patients from ward 5 can go to for further psychiatric care and support. If a patient is unable to move into a group home or one of the country's rehabilitation centers, then they must remain in the hospital until a place is available. However many patients who are able to live outside of the hospital cannot due to lack of space and resources.

Although the National Psychiatric Hospital does not have regular access to current medical technologies, it does have the support of a laboratory, electroencephalogram (EEG), and an electro convulsive therapy unit, which provides more than 6000 therapies a year (about 20-25 per day). There is also a medical unit, providing care and treatment of physical disorders by internal medical physicians. As well as in-patient services, there are also outpatient services handling more than 1000 patients and offering a variety of individual and group therapy programs. One program, called "Daytime Hospital" gives patients the opportunity to develop skills to do simple tasks, i.e., producing merchandise that is sold to the public such as piñatas and articles of clothing.

Methods: Observations and Analysis

To understand the key social and ethical dilemmas involving community-based rehabilitation for mentally ill patients living in Costa Rica, I carried out participant observation in the summers of 2002 and 2003 at the National Psychiatric Hospital; I observed what healthcare teams and their patients experience while working and living within and outside of the hospital environment. To support my observational findings I interviewed clinicians and nurses working at the National Psychiatric Hospital and discussed with area families, including two families I lived with, their perceptions of mental disorder and the benefits and burdens of CBR. I also reviewed recent proposals by clinicians at the National Psychiatric Hospital for the initiation and development of mental healthcare programs in Costa Rica. My analysis of the ethical and social dilemmas surrounding CBR is supported by a review of recent literature on community psychiatry and rehabilitation programs for physically and mentally disabled persons around the world.

Findings: Developments toward Community-based Rehabilitation

Patients at the National Psychiatric Hospital receive medications, psychotherapies, and electro convulsive therapies depending on the type of mental disorder they have and on the frequency of symptoms associated with the disorder. Although these methods are useful for meeting some of the biological and psychological needs of patients, community-based rehabilitation programs have the potential to meet all of the biological, psychological, and social needs of patients. These social needs include providing spiritual support, acknowledging cultural differences, developing communicative and other social skills for interacting with others, and creating a network of friends and co-workers who view and respect the patient as a person, and not as a disease or illness. As Drake,

Green, Mueser, and Goldman (2003, p. 434) explain, while somatic and psychosocial treatments focus on controlling illness, rehabilitative interventions “primarily aim toward improving functioning and quality of life rather than reducing the symptoms of the illness.”

Developments have been made to integrate hospital-based care with community-based care as a way to show the CCSS and community leaders that community mental health is beneficial for treating patients and meeting all of their biopsychosocial needs. Instead of institutionalizing mentally ill patients in a static, clinical environment, the philosophy of the National Psychiatric Hospital is to allow patients to develop important daily life skills, recognize and accept their physical and mental disabilities, and get effective medical treatment so as to rehabilitate them for community integration.

In helping patients develop important daily life skills, healthcare professionals at the National Psychiatric Hospital have implemented a task-based program known as “Daytime Hospital” where patients can learn important skills such as reading/writing, sewing, woodworking and working with crafts (some of which can be sold to buyers outside of the hospital community). Daytime Hospital is run by the CCSS and functions as a halfway rehabilitation center. Patients are supervised by social workers and occupational therapists though the majority of assistance and supervision is provided by volunteers. Similar halfway rehabilitation centers are located in Desamparados, Hatillo, Naranjo, and Alajuela, (located near San Jose) and are supported by the community, the CCSS, and the National Rehabilitation Center, a publicly funded organization that has made successful attempts to implement these community-based programs throughout Costa Rica. Most of the patients working at the halfway rehabilitation centers outside of the National Psychiatric Hospital have supportive families; they have the freedom to work during the day at the centers and then leave for home in the afternoon.

Clinicians, social workers, therapists, and volunteers working at these halfway rehabilitation centers believe that having the opportunity to learn skills not only builds patients’ self-esteem but also gives them the freedom to gain some control over their lives. Those who contribute to these programs oversee the work that is done by the patient, but more importantly, are able to guide and provide emotional and psychological support to the patient when needed. Unfortunately, the “Daytime Hospital” program, like many CBR programs, lacks significant financial and clinical resources, and because of this, some of the halfway centers have closed due to a lack of funding, thus forcing patients back into their homes or out on the streets.

In another ward of the hospital, several areas are designed for the Daily Life program, a program where healthcare professionals help patients develop a sense of independence by teaching them important personal care skills. Patients learn how to shop for food and clothing, cook, bathe and dress themselves. These basic skills are viewed by healthcare professionals as therapeutic for some patients, e.g., calming the anxious or emotionally disturbed patient, and providing a critical step for others who are able to take on the responsibilities of daily living in a community.

Although healthcare professionals at the National Psychiatric Hospital are preparing patients for community integration through their basic skills programs, it remains unclear as to whether the focus should be on CBR for delivering optimum care to mentally ill patients. The publicly-funded National Rehabilitation Center, along with the CCSS, have tried to develop and implement various programs, such as “The Daytime Hospital” program, but since there is a lack of adequate resources for implementing and expanding these programs, making CBR central to mental healthcare in Costa Rica, these programs are insufficient for delivering optimum care to mentally ill patients. Unfortunately several hospitalized patients (an estimated 200 patients) are ready to live and work within their communities, but they may face a lifetime of hospitalization if they cannot get the help they need through CBR programs that are financial stable and rich in resources. However, as I have found, in order for CBR to be successful in countries such as Costa Rica, financial stability and resource dependability are not enough for helping patients with mental illnesses. In determining whether Costa Rica is ready for CBR, one must take into account several ethical and social considerations. Several questions need to be answered. For example, is CBR

more or less restrictive than involuntary hospitalization (Davis, 2002), are communities willing to support CBR programs even when members fear mental illness, will healthcare professionals and volunteers protect the patient's right to privacy, etc.?

Is Costa Rica Ready for CBR?

In looking at community-based psychiatry, Szmukler (1999, p. 363) recognizes that several developing countries, such as Costa Rica, are dramatically moving from hospital based programs to community based rehabilitation programs. In this shift to community-based psychiatry, e.g., CBR programs, multidisciplinary approaches in care and treatment are identifiable; such approaches in treatment recognize that patients with mental diseases are biological, psychological, and social persons.

When looking at community psychiatry there is a clear shift from institutional based medicine to community based medicine where there is an expansion in the network of caregivers and services and a development in the dynamic relationship between the medical community and the community at large. Szmukler (1999, p. 364) writes that community based psychiatry "aims to establish a network of services offering crisis interventions continuing treatment, accommodation, occupation, and social support which together help people with mental health problems to retain or recover social roles as close to normal as possible for them." Although a team of physicians, nurses, and other healthcare professionals may work with patients in the hospital setting, the number of non-professional and professional caregivers increases once the patient enters the community. Friends, family, social workers, governmental and non-governmental organizations, group home personnel, employers, etc. may all contribute to the overall care of the patient, including his or her biological, social, spiritual, and cultural needs. It is in community psychiatry where the network of healthcare providers is as complex as the environment in which care is delivered.

Besides providing psychotropic drugs and psychological interventions, such as psychotherapy, CBR programs are designed to integrate patients into a community where they can work towards regaining or developing basic living skills. Although these basic living skills can be taught within a hospital, as I observed at the National Psychiatric Hospital, it is not until the patient is outside of the controlled environment of the hospital when he or she can apply and fully understand the implications for learning basic living skills.

CBR can have a profound effect on patient's physical, psychological, and social wellbeing; patients develop a sense of independence and learn to control their lives without letting their mental disorders control them. Although, reaching goals of independence and self-sufficiency can be a difficult process for both patient and community even when CBR programs are in place and fully functioning. Contributing to this difficult process are several social and ethical dilemmas surrounding CBR. In highlighting these social and ethical dilemmas it becomes clear that CBR may not, given the current financial status of CCSS and the unsustainable nature of CBR programs in general (Turmusani, Vreede, and Wirz., 2002), be an appropriate course of action for Costa Rica.

Ethical and Social Dilemmas Surrounding Community-based Rehabilitation

While the shift from hospital-based medicine to community-based medicine may benefit individual patients' health there are some possible concerns to consider. First, as Szmukler explains, the shift from hospital to community-based medicine may exert pressure to discharge patients quickly (Szmukler, 1999). Although the goal of this shift in medical practice is to rehabilitate patients for community living, this goal can only be achieved with careful planning and monitoring. Patients ought to meet and maintain standards set by the healthcare institution(s) prior to their community integration, the role of healthcare professionals and others involved in CBR should be one of "allies and resources", and the community should be well informed of CBR and related policies prior to their participation (Turmusani, Vreede, and Wirz 2002). Community mental health may become an unachievable or unrealizable goal if responsible community health leaders do not properly plan, deliver, and evaluate CBR programs. For example, if community health leaders do not provide information about procedures, possible obstacles, and the goals of CBR in a clear and comprehensible manner, especially to patient-participants, CBR programs are subject to failure. Singh (2000, p. 414) writes that community mental health

teams are often criticized for their “ambiguous and overambitious aims, and their tendency to neglect people with the most challenging health- and social- care needs”. If community mental health workers, including clinicians, community leaders, social workers, nurses, and others, are unwilling to work together as a team and are not fully committed to the careful planning and implementation of CBR, the program is subject to failure and the patient’s health is in jeopardy. The community mental healthcare setting is a resource-poor system (Christensen, 1997 p. 6) and without a team-approach in delivering care, clinicians may carry the burden of assuming the role of gatekeeper, or worse yet, fail to meet their patients’ needs.

One problem for Costa Rica is overambitious mental healthcare teams and not-so-ambitious communities who may be reluctant to participate and work together as a team toward CBR for persons with mental illnesses. Even though the culture of Costa Rica is that of close-knit families and communities whose major concern is their health, Costa Ricans generally have a laid back attitude when it comes to getting things done, including the development and implementation of healthcare programs. In some respects this attitude can be viewed as a healthy one as they experience less stress and anxiety in trying to meet deadlines, keep appointments, and satisfy their customers, friends, or family. However, this attitude can be especially problematic after a project or program has been initiated; it takes a long time for a project or program to be fully implemented and assessed. Thus, in order for CBR to be a significant part of mental health care in Costa Rica, healthcare professionals and community members need to be willing to participate and work together, and work with a strong commitment to improve patients’ mental health through rigorous CBR program development and assessment.

Another problem that often occurs when mental healthcare teams are overambitious is improper outpatient treatment; patients may be coerced to live in the community or discharged too quickly from the hospital. If patients are coerced to live in the community as an alternative to hospitalization, paternalistic healthcare teams are interfering with the patient’s freedom to choose and act with self-determination regardless if CBR will be the best course of action to meet the healthcare needs of the patient. Christensen (1997, p. 8) writes, “In essence, the concept of paternalism represents a classic example of a conflict between meeting a client’s needs (as determined by the provider) versus respecting a client’s rights to self-determination. Involuntary commitment, forced medication, and coerced out-patient treatment are some modes of psychiatric practice viewed as paternalistic.” Unlike involuntary or coerced hospitalization and forced medication (where the justification to act paternalistically is to protect the patient from harming himself/herself and others), if a patient is coerced or discharged too quickly there is no moral justification. The patient is wrongfully forced into an unconfined environment that will most definitely harm rather than protect him or her. Not being able to cope with daily living outside of the hospital may lead to further physical and mental distress, possibly making the patient feel like a failure as he or she reverts to abnormal thoughts and behaviors experienced and expressed prior to rehabilitation. Having been institutionalized for an extended amount of time, combined with having a debilitating mental disorder, the patient’s first experiences outside of the institution can be especially detrimental to his or her psychological and physical well being if he or she has not been properly prepared to live in an often disorderly and confusing community environment.

A related concern regarding CBR is that rehabilitation is not a permanent solution for delivering the kind of care or treatment the patient needs. This may be an important concern if rehabilitation is viewed as a single goal – helping the mentally ill person to live within a community. If a patient can learn to cook, clean, dress, and work while receiving necessary medical treatments outside of the hospital, the patient appears to be getting the type of care he or she needs. However, this type of rehabilitation program, focusing on just the medical and social needs of the individual is subject to failure and is not a permanent solution. A rehabilitation program that can meet the psychological needs of the patient as well as the social and medical needs will less likely fail. An effective rehabilitation program recognizes the changing psychological needs of the patient as he or she integrates into a community.

If the patient appears to be ready for discharge, that is, has shown considerable progress and success in his or her

basic skills programs and has begun to develop interpersonal skills that would assist the patient in adapting to a new environment, then CBR should be an option for this patient. However, the difficulties lie in determining which skills are necessary for living outside of the hospital and when a patient has sufficiently developed those skills. Furthermore, once a patient has been discharged, how will healthcare providers, along with community members, adequately help the patient to maintain those skills? These difficulties can be resolved with careful planning and assessment, though many countries like Costa Rica do not have the resources and management to do this, which brings us to a second dilemma for CBR: there are not enough healthcare providers to assist in rehabilitation programs.

Many Patients, Few Resources

Unfortunately developing countries such as Costa Rica do not even have enough healthcare providers to help all people receive basic care, especially those with mental disorders. If CBR programs were to be implemented in Costa Rica without having enough healthcare teams to assist both hospitalized and non-hospitalized patients, such programs would fail; patients living in the hospital or out in the community would not receive adequate care. Because there are not enough resources currently in Costa Rica to implement effective CBR programs, measures ought to be taken to either acquire these necessary resources, e.g., more psychiatric teams, or forgo rehabilitation programs until resources can be made available. Unfortunately, regardless of having a national healthcare system, the people of Costa Rica are not receiving adequate mental healthcare and the programs that can provide more and better mental healthcare services cannot be implemented due to a lack of resources. This, I believe, is partially due to the division between physical and mental illnesses.

Although many of the psychiatrists in Costa Rica practice Western medicine with the view that physical and mental illnesses are not easily separable, the CCSS does not view mental healthcare as a priority, as evidenced by the lack of hospitals, psychiatrists, and technology needed to diagnose and treat patients with mental illnesses. While Costa Rica has made great strides in delivering healthcare to its citizens, the focus is on basic and preventative care through better education and country-wide immunization programs. Success has been measured by low infant mortality rates, a decline in childhood diseases and diseases associated with poor nutrition, and life expectancy rates equivalent to first order nations such as the United States and Japan. However, there has been a significant rise in spousal and child abuse and drug and alcohol related diseases. Although these problems do not go unnoticed, they are not always viewed as physical and mental healthcare problems that can be identified and treated by community intervention and support. These types of problems may continue to rise if mental healthcare is viewed as a separate and distinct form of healthcare and if there is a lack of will to provide mentally ill patients with the resources they need.

Public Fears

Another dilemma for healthcare professionals, patients, and the community are the public fears surrounding mental illness. Depending on the cultural background of the community these fears may vary. Some members of the Costa Rican community may believe that mental illness is a distinct, contagious entity, which should be contained, i.e., mentally ill persons should be confined to a medical institution to prevent the spread of the disorder. Others believe that the mentally ill persons pose a risk to the community either by harming themselves or others within the community and claim to have witnessed public displays of aggression and self-mutilation, e.g., “A crazy [autistic] man banged his head against a stone wall repeatedly until he bled to death” (story told by a woman from San Jose, 2003). Stories about mentally ill patients murdering innocent bystanders or making obscene public gestures are not uncommon. Many of these stories are fabricated and are intended to scare their readers and listeners in the same manner as ghost stories. The greatest fear lies in not the fear of being harmed by someone with a mental illness but the fear of having to care, protect, and accept the mentally ill person. Though cases of mentally ill patients inflicting harm on themselves or others are rare, by educating and training community members and patients about mental disorders and the persons who have them fears can be lifted and possible harms can be prevented. Szmukler (1999, p. 374) explains, “Fear of the mentally ill is omnipresent. Care in the community treads a fine line. If it is not managed successfully ‘there is a danger that progress over

recent decades in emphasizing the individuality of patients and affirming their rights (and responsibilities) within a therapeutic relationship could be compromised by early resort to unnecessary inpatient supervision and coercive models of care”.

Even though the public may be supportive of CBR and have little or no fears about having mentally ill patients integrate into the community, many community members may not understand their role in helping the patient acquire the freedom and dignity that s/he deserves. Some community members may believe that ‘helping’ means monitoring the patient’s every move, fixing any mistakes that are made by the patient, or doing things that the patient is capable of doing for himself/herself, e.g., preparing meals, cleaning, and so forth. Although these members of the community believe they are helping, they are infringing upon the patient’s rights and responsibilities and are doing more harm than good by not permitting the patient to learn from his or her mistakes or by not allowing the patient to develop a sense of pride by completing his or her own daily tasks. Other members of the community may ignore or shun the patient, not because they are fearful of the patient and his or her illness, but because they do not know how to help. This too is problematic for the patient because s/he may feel ashamed, believing s/he is doing something wrong, or embarrassed that s/he is different from other members of the community. Again, to eliminate the stigmas associated with mental illness and to respect the patient’s dignity and self-worth, the community needs to be informed of how to help patients without infringing on their rights and responsibilities.

Patient Autonomy and Confidentiality

As briefly stated above, another difficulty with CBR involves the possible disregard for patient autonomy, which may result in the breakdown of trustful healthcare team-patient relationships. Recognizing autonomy is recognizing the inherent worth of the patient – the patient as a person. This means that, as a person, the patient is self-determining and should be permitted to decide what is in his or her own best interests. Patient autonomy is critical for developing a symbiotic relationship with healthcare professionals where the patient can play an active role in medical decision-making and exert some control over the treatment process without manipulation or coercion. Although autonomy may be compromised if the patient has a debilitating mental disorder and is unable to make rational decisions, one should not view the patient as a being with no inherent worth or interests. If a patient is unable to fully understand and make rational decisions, healthcare providers should make an effort to relay pertinent information in a way the patient can understand and respond to through his or her expression of beliefs, values, and opinions. In cases where CBR has been implemented in developing societies, patients are respected as persons and generally have more autonomous control over their lives as they become fully integrated into the community than if they were to live in a hospital setting. However, patients may not have control over every aspect of their lives, especially when it comes to healthcare professionals disclosing their private information to third parties, including community members, employers, and agencies participating in CBR.

Information between healthcare professionals and patients is, as a general rule, kept confidential to maintain a trusting therapeutic relationship. However, there are circumstances in which private information may be made public. It may be necessary to divulge private information about a patient if not doing so will result in the harm of the patient or others. For example, in community based rehabilitation it may be necessary to divulge private information, e.g., the patient has a history of violence towards himself or herself, to protect the patient and/or community. With such information community members who are assisting patients in their daily lives can prevent the patient from harming himself or herself. The paternalistic act of divulging confidential information to third parties may be viewed as necessary, i.e., to protect and look out for the best interests of the patient. On the other hand, the disclosure of private information about a patient can lead to unwarranted violations of privacy, thus compromising the psychological well-being of the patient, e.g., making him/her feel inferior, different, etc.

CBR is a way to provide care through a much larger network of both professional and non-professional healthcare providers. And, as the network expands, confidential information may be passed along without the patient knowing. However, patients may not know that their private information has been disclosed to third

parties, including employers, neighbors, and agencies, and are possibly subjected to unfair treatment as their conditions become exposed. And, since the patient does not know and has not given prior consent for private information to be released to a third party, s/he cannot act as a self-determining agent and is thus, disrespected as a person. Even in cases where breaching confidentiality is necessary for protecting the patient and others from harm (i.e., Tarasoff Case), it should be clearly explained to the patient that such private information may be disclosed to third parties and reasons why disclosure is important.

Conclusions: Recommendations for Mental Healthcare in Costa Rica

The future of CBR in Costa Rica depends on whether enough resources can be provided, including a sizable increase in the number of psychiatrists, the willingness of the community to help patients, and a better understanding of mental illness and the patient as a person. In order to provide enough resources to fully implement CBR, mental healthcare must be viewed as a priority. To date, mental healthcare in Costa Rica is not a priority for the CCSS even though the leading healthcare problems in the country are related to mental illness (e.g., spousal and child abuse and drug and alcohol abuse). Given the current state of Costa Rica's mental healthcare system, there is a greater need to focus on delivering mental healthcare services to all who could do with of such services. And, to do this, efforts to expand clinical resources, especially the number and availability of psychiatrists, should be made prior to any further developments of CBR. Until there is an adequate number of mental healthcare professionals who can work with community leaders and patients toward a better system of biological, psychological, and social care, along with an understanding of the social and ethical obstacles healthcare teams and patients may face, CBR should be viewed as a future goal. However, the steps Costa Rica has taken toward this goal should be acknowledged as important ones; by creating various programs such as "Daytime Hospital", and seeing both the positive and negative effects of these programs, Costa Rica is beginning to understand the clinical, social, and ethical needs of her community and establishing a path toward an even better system of health.

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Instrumentalism in occupational therapy: An Argument for a pragmatic conceptual model of practice

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Abstract

The purpose of this paper is to present an argument for a conceptual model that can be used by occupational therapists to apply the pragmatic construct of instrumentalism in their practice with clients. Instrumentalism refers to the view of the human mind as a tool for adaptation to the environment (Dewey, 1996a). The use of instrumentalism provides a way of accessing the client's mind to facilitate adaptation through occupational performance. It is argued that this instrumental use of the mind in rehabilitation would help occupational therapists to develop holistic, occupation centered practice based on a sound philosophical framework. In the paper, it is asserted that viewing the mind as an instrument for adaptation to the environment and accessing it for occupational performance in therapy is in keeping with the historical origins of the profession and therefore enhances the profession's unique identity.

Introduction

Wood, Nielson, Humphry, Coppola, Baranek, and Rourke (2000) state that there is a need to educate occupational therapists with skills that prepare them for practice that clearly demonstrate the uniqueness of occupational therapy. However, a literature review indicates that occupational therapy students graduate with a fragmented knowledge base and are not well prepared for practice that is based on a firm knowledge of the

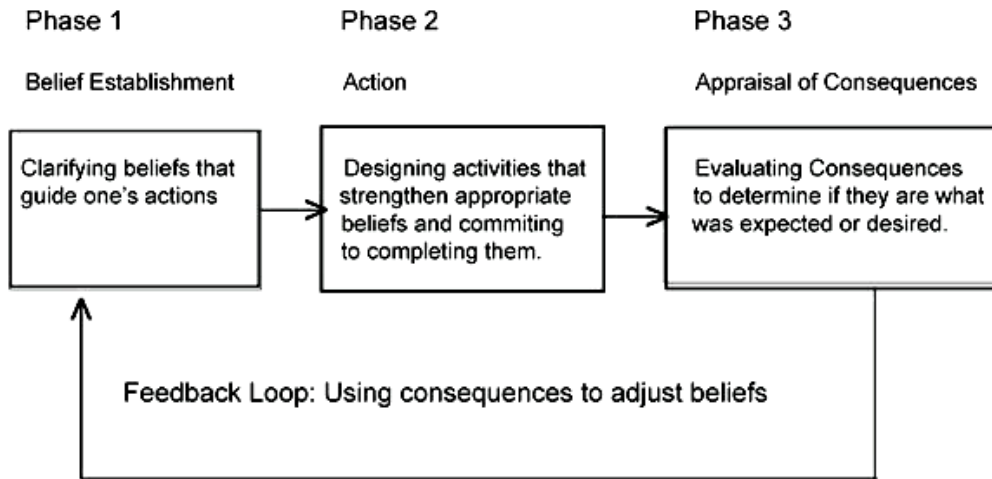
nature of occupation (Peirce, 2001). They spend more time acquiring component based physiological and medical facts instead of occupation-based knowledge (Peirce, 2001; Stern & D'Amico, 2001).

In a study to evaluate the congruity between the intended and actual outcomes of problem based learning, Stern and D'Amico (2001) found that students' perceptions regarding their learning outcomes were consistent with the faculty's objectives. However, further examination of the case based learning objectives that were set for the students by faculty indicates that many of them were geared towards medical understanding of the conditions rather than application of occupation as intervention. Out of the 20 objectives for the three case studies, 9 (45%) were oriented towards the medical aspects of the cases. They included objectives such as, "Medical complications associated with cerebral palsy", "Medical options for managing spasticity", "Orthopedic management of secondary conditions related to cerebral palsy", and so on (p. 458). The remaining 11(55%) objectives which might be seen as pertaining to the application of occupation were not explicit regarding what the students were required to learn about application of occupation as intervention. They included objectives such as, "The impact of impairments on functional performance associated with spinal cord injury" (without specifying what 'functional performance' meant), "The occupational therapist's role", and "The concept of role change", (The last two more explicitly addressing the application of occupation as intervention) (Stern & D'Amico, 2001, p. 458). While it is desirable that students understand the medical aspects of conditions that therapists address in practice, it seems that according to the objectives set in this study, emphasis was placed on discussing those medical aspects, deemphasizing a thorough study of application of occupation as intervention. Furthermore, students indicated that objectives directed towards understanding of the medical conditions were met more frequently than those directed towards understanding occupational functioning of clients.

In addition, Doyle, Madigan, Cash, and Simons (1998) indicated that since the 1970s, there has been a trend for increasingly fewer therapists choosing to practice in the area of mental health. Penny, Kasar and Sinay (2001) concurred that occupational therapy is becoming less involved in mental health practice. Considering that the practice of occupational therapy historically originated from mental health (Bing, 1981; Peloquin, 1991), the departure from this area of practice indicates the profession's loss of identity. In order to regain that identity, it is necessary, as Wood, et al. (2000, p. 591) contend, for occupational therapists to engage in an "... in-depth study of the social movements and philosophies that gave rise to the idea of occupation as therapy...in addition to modern approaches to studying occupation...". Such movements and philosophies include the moral treatment, pragmatism, and the mental hygiene movement (Barton, 1980; Bing, 1981; Bockoven, 1971; Breines, 1986; Dunton, 1957a; Peloquin, 1991; Pinel, 1962; Woodside, 1971). All those movements and philosophies emphasized the role of the mind in enabling human engagement in occupation so as to interact with the environment adaptively.

The purpose of this paper is to present an argument for a proposed conceptual model of practice that is based on the philosophy of pragmatism, which has been suggested to be the philosophy that guided the maturing of the idea of occupation as therapy (Breines, 1986; Hooper & Wood, 2002). Practice based on such a philosophy would be consistent with the occupational therapy roots in mental health because it would provide interventions that are primarily based on the concept of the mind as a means of activating mind-body action through occupation. In the proposed model, the pragmatic construct of instrumentalism (Dewey, 1957; 1996a; 1996b) will be operationalized for application in practice which centers on the notion of the mind as an instrument which can be accessed to facilitate occupational functioning thus promoting the client's adaptive interaction with his/her environment. The model comprises three phases: The belief establishment, Action, and Consequence Appraisal phases (see figure 1).

**Figure 1. Illustration of Instrumentalism in occupational therapy:
A pragmatic conceptual model of practice.**



The belief establishment phase consists of clarification of beliefs that guide a person's actions in occupational functioning, in an attempt to enhance instrumental use of the mind in occupational performance. Beliefs that hinder effective occupational performance are identified and occupational activities are presented to assist the client to challenge them. New beliefs that support desired occupational functioning and subsequent consequences (outcomes) are developed when necessary. In the action phase, the client makes a commitment to act in accordance with the newly established, more adaptive beliefs, until such beliefs become ingrained in his/her mind as a guide to the person's occupational activities. In the third and final phase, the consequences of actions resulting from the newly established beliefs are examined. If such consequences are what the client desired, therapy is considered to have been successful and is terminated. If such consequences are not what the client desired, the therapist guides him/her back to the belief establishment phase. Beliefs are re-examined to determine if they support action that is in accordance with the desired occupational performance, and the therapeutic process begins all over again.

The Construct of Instrumentalism defined

Since the proposed conceptual model is based on the pragmatic notion of instrumentalism, it is necessary at this point to define the construct. According to Dewey (1996a), pursuit of knowledge by human beings is for the purpose of controlling nature, by correlating objects of experience and using the correlations to make desirable changes in the environment. As such, "... the goal of knowledge, the fulfillment of its aim in discovery of these correlations, is equivalent to placing in our hands an instrument of control" (p. 349). Since knowledge is acquired through operations of the mind (for instance correlation of the objects of experience is achieved by thinking, which is a function of the mind), it follows that Dewey views the mind as an instrument that a human being uses for the purpose of controlling his/her environment, or as Darwin (1985) proposes, adapting to the environment. Dewey's instrumental view of the mind is even clearer in his statement that: "When it is apprehended as a tool and only as a tool, an instrumentality of direction, the same scrupulous attention will go to its formation as now goes into the making of instruments of precision in technical fields" (Dewey, 1996a, p. 375). The proposed conceptual model of practice is designed to provide guidelines that

occupational therapists can use to access the mind as an instrument for facilitation of human adaptation to the environment.

Development of the Conceptual Model

Mosey (1996) provides a five step format for the development of sets of guidelines for practice. These steps are: analysis of an enigmatic problem, identification of theoretical information to form a theoretical core, selecting and synthesizing postulates to form a theoretical core, deducing guidelines for problem identification and intervention, and assessment of the completeness of content and internal consistency. The proposed conceptual model was developed in three parts following Mosey's (1996) guidelines as explained above. This paper consists of part one, in which the problem is stated, the proposed conceptual model of practice outlined, and a rationale for choosing sources of theoretical constructs/concepts for the model stated. In part two, a theoretical core will be articulated. Guidelines for problem identification and intervention will be outlined in part three. Parts two and three will be presented in two other papers.

Definition of the problem

Various frames of reference have been developed which offer guidelines for patient assessment, treatment planning, and intervention (Bruce & Borg, 2002; Christiansen & Baum, 1997; Creek, 2002; Kielehofner, 1997; Neistadt & Crepeau, 1997; Schultz & Schkade, 1992; Schkade & Schultz, 1992; Stein & Culter, 2002). Each of the frames of reference approaches human occupational problems in a unique way. For example, the Occupational Adaptation frame of reference conceptualizes the human being as a system consisting of the sensorimotor, psychosocial, and cognitive subsystems. Humans are conceptualized as interacting with and adapting to their environment through occupation using the three subsystems (McRae, Falk-Kessler, Julin, Padila, & Schultz, 1998; Schkade & Schultz, 1992; Schultz & Schkade, 1992).

The Model of Human Occupation (MOHO) also views the human being as a system in interaction with the environment (Kielhofner & Burke, 1980; Kielhofner, 1985; 1997). The Cognitive Disability frame of reference is concerned with the cognitive dysfunction, which is seen as originating from the brain structural/biological pathology (Allen, 1982; 1985; 1996; Earhart, Allen, & Blue, 1993). The life-style Performance Model focuses on the occupational lifestyle that is understood to sustain health and to enable life satisfaction (Fidler, 1996). The Canadian Model of Occupational Performance emphasizes interaction between the person, environment, and occupation (Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 1998). The Cognitive-Behavioral Frame of Reference is closest to the conceptual model proposed in this paper in that it is based on the assumption that thinking (cognition) affects behavior. The thrust of the frame of reference is to change thoughts that are believed to cause specific behaviors while assisting the client to develop a knowledge base for problem solving (Bruce & Borg, 2002). Therefore, its goal is to help the client regulate him/herself through change of thoughts, behavior, and environment (Stein & Cutler, 2002).

In all the above models, and many others, the theme of a person who is in interaction with the environment through occupational performance is apparent. There is general recognition that motivation for action is for individuals to meet their internal needs and environmental challenges (Kielhofner, 1997; Mcrae, et al., 1998; Schultz & Schkade, 1992; Schkade & Schultz, 1992) and that cognition is the determinant for human behavior in his/her environment (Bruce & Borg, 2002; Stein & Cutler, 2002). However, the exact nature of human occupational needs, how they arise, and their purpose, is not clear. Also, the philosophical orientation or system on which these frames of reference are based is not apparent. Perhaps this is why it is so difficult to follow their guidelines to establish occupationally based practice (Blanche & Henny-Kohler, 2000; Wilcock, 2000).

This difficulty was particularly emphasized by informal feedback from students in one occupational therapy program in which this author taught. Many students in this program reported, during one of the informal debriefing sessions after their level I fieldwork affiliation in physical disabilities, that their clinical supervisors

emphasized upper extremity exercises, ambulation, manual muscle testing, splinting, assistive devices, and techniques such as NDT (Neurodevelopmental techniques) in their interventions. One student stated that she observed therapists in the clinic engaging patients in, “restorative programs involving walking and upper extremity exercises and some grooming activities”.

According to these students, it seems that occupations that were meaningful to the patients were rarely used. Seldom was there collaboration between patients and therapists regarding treatment planning. Therapists designed treatment plans, which often were identical for all patients and frequently in the form of checklists of exercises and activities. This type of treatment plan did not encourage discussion of the interventions with patients. One student described the therapists’ behavior in the facility where she completed her affiliation as follows: “They threw activities at patients and went to the office to do their own things. They did not seem to want to know patients. For example, one patient liked sewing activities but this was never picked on by the therapists”. Another student stated that her supervisor, “. . . had no patience with patients”. Such feedback suggests that in these students’ experience, in their clinical affiliation, attempts to take patient’s interests into consideration, to individualize therapeutic interventions to the specific needs of the patient, and to contextualize therapy were often not made.

In this paper, it is argued that infusing a philosophical perspective might help establish a clearer, more unified view of the human being as an occupational being, improve therapists’ understanding of the nature of interaction between humans and their environment, and clarify the end to which this interaction takes place. It is proposed that the wisdom of the founders of occupational therapy such as Pinel (1962) and Tuke (1964), who founded the moral treatment movement, which was the precursor of occupational therapy, and Barton (1980), Dunton (1957a; 1957b), and others who formalized occupational therapy at the turn of the 20th century, be consulted, to ensure uniqueness of occupational therapy based on a sound philosophical framework. A literature review reveals that these patrons of the profession emphasized centrality of the mind in occupational therapy intervention. For instance, Pinel (1962, p. 193-194) described this primary focus on the mind using occupation thus: It was pleasing to observe the silence and tranquility which prevailed in the asylum de Bicetre, when nearly all patients were supplied by the tradesmen of Paris with employments which fixed their attention, and allured them to exertion by the prospects of a trifling gain.

According to the above statement by Pinel, the goal of intervention at the Bicetre was to arrest patients’ attention. Attention is a function of the mind, and therefore, it can be argued that the intervention focused primarily on facilitating proper functioning of the mind and through the mind, appropriate functioning of the body. Similarly, Samuel Tuke (1964, pp. 151-152) explains the treatment of patients with depression thus, “Every means is taken to seduce the mind from its favourite but unhappy musings, by bodily exercise, walks, conversation, reading, and other innocent recreations.” Once again, the focus of intervention by Tuke was the mind, using occupational activities that require mind-body involvement. Similarly, in the principles of occupational therapy that were formulated after formal founding of the profession in the 20th century, the importance of motivating patients, even when the intended purpose of therapy was to facilitate physical rehabilitation, was emphasized. In this regard, Licht (1957) stated that:

... In motivating the patients to accept and benefit from occupational therapy, there should be a skillful blending of two important elements: first, meeting the individual interests and abilities, and secondly, providing activity which will attain the prescribed objective in terms of physical and mental treatment. If the former is lacking, the patient might be better handled by exercise alone.

Thus, once again, the primary focus of therapy is motivation since this is primary to engagement in any occupational endeavor. To motivate the patient, the mind must be engaged through exploration of individual interests and abilities. It is therefore clear that historically, the primary focus in occupational therapy was

engagement of the mind, and through the mind, facilitation of a holistic mind-body function. The proposed conceptual model aims at emphasizing that approach to therapy, irrespective of the field of practice (whether physical disabilities, geriatrics, psychosocial, home health, etc.). In this regard the model would offer practicing therapists one more way of conceptualizing therapy where the human mind is seen as an instrument for human functioning and adaptation to the environment. The theoretical core that supports the outlined conceptual model will be formulated from constructs/concepts derived from the historical literature of occupational therapy, the philosophy of pragmatism, and the complex dynamical adaptive systems theory.

Justification for the chosen sources of the theoretical core

The historical literature of occupational therapy from which the theoretical constructs/concepts will be chosen goes back to the moral treatment movement in Europe in the second half of the 18th century. For the first time, occupation was used as therapy to treat the mentally ill by the founders of this movement such as Pinel and Tuke (Bing, 1981; Bockoven, 1971; Hergenhahn, 1997; Peloquin, 1991). This movement was part of an effort to reform mental health in France and England (Bing, 1981; Hergenhahn, 1997). Before the moral treatment movement, the mentally ill were believed to be possessed by evil spirits, or that they were being punished for the sins of their parents and grandparents. Bloodletting, flogging, and other cruel forms of treatment were used in an attempt to expel evil spirits from the patients (Bruce & Borg, 2002; Hergenhahn, 1997). Patients were restrained physically because they were believed to be violent and unmanageable by other methods. In their reform efforts, Pinel in France and Tuke in England introduced use of occupation, decent food, kindness, and a comfortable environment as methods of treating the patients and prohibited use of restraints and other forms of cruel treatment (Pinel, 1962; Tuke, 1964).

The principles of moral treatment were introduced in the United States of America by the Quakers, who had either visited mental health institutions where such principles were used, or had been educated in Europe (Bing, 1981; Bruce & Borg, 2002; Creek, 2002). By the second half of the 19th century, however, due to a variety of reasons, the moral treatment movement died in the USA. The principles of moral treatment were re-discovered at the turn of the 20th century by the founders of formal occupational therapy, such as Dunton and Barton. Evidence of this rediscovery of the moral treatment principles is best illustrated by Dunton (1957a, p. 4) who stated that: "The activity programs for mental patients were termed work-cure, moral treatment, ergotherapy and many other names." He continued to demonstrate his acquaintance with the works of the founders of the moral treatment movement by writing: "Philippe Pinel was probably the first to express the more modern viewpoint in 1791 (2), in that part of his Treatise on Moral Treatment of Insanity." Such historical connections give credence to the statement by Bockoven (1971, p. 223) that: "It appears almost conspicuously evident that moral treatment could be reasonably described in philosophy and practice as comprehensive occupational therapy program." For a conceptual model, such as the one proposed here, to be complete, it is necessary that its constructs be derived from the entire occupational therapy history dating back to the moral treatment era.

Apart from the moral treatment movement however, it has been suggested that the American philosophy of pragmatism influenced the development of occupational therapy significantly. For example, Breines (1986) argues that the roots of the profession are to a large extent to be found in pragmatism. This is evident in the fact that historically many important personalities in occupational therapy history, such as Julia Lanthrop and Jane Addams who ran the "Hull House" in Chicago, were associated with leading pragmatic philosophers such as John Dewey and George Herbert Mead, who also participated in the social experiments at the "Hull House". The goal of the "Hull House" project was to help integrate poor emigrants into the American culture using occupations (Breines, 1986; West, 1989). Also, Eleanor Clarke Slagle, who greatly influenced the development of occupational therapy for more than 30 years (Bing, 1981), studied at the Chicago school of Civics and Philanthropy with Jane Addams and Julia Lanthrop, and was also associated with the "Hull House" (Breines, 1986). Furthermore, Adolf Meyer, who wrote "The Philosophy of Occupational Therapy" (Meyer, 1977), was a close associate of Jane Addams, Eleanor Clarke Slagle, Julia Lanthrop, and was

acquainted to pragmatic philosophers William James, Charles Sanders Peirce, and John Dewey. With these historical connections between influential personalities in occupational therapy and the pragmatic philosophers, it is reasonable to assume that as Breines (1986) asserts, occupational therapy was application of pragmatic principles in the field of health.

If we accept the argument that the philosophy of pragmatism was a major influence in the development of occupational therapy, we have also to accept the influence to occupational therapy, through pragmatism, of British empiricism especially the philosophy of John Locke, and Darwin's theory of evolution. Both British empiricism and Darwin's theory of evolution were significant influences to the development of the philosophy of pragmatism (Buchler, 1955; Fisch, 1996). Indeed, the founder of pragmatism, Charles Sanders Peirce (1955), considered Darwin's work to be extremely important because, according to him, Darwin "...proposed to apply the statistical method to biology" in his theory of the evolution of species. The influence of empiricism and Darwinism is illustrated in all the pragmatists' literature in their emphasis on the value of experience in helping the human being to interact with and control his/her environment. It is especially evident in the literature of John Dewey, who went on to propose that the human being is not removed from nature but is part of it, and the human mind is an instrument used to facilitate adaptation to the environment (Dewey, 1957; 1996a). The construct of instrumentalism is a core construct in the proposed conceptual model.

Acknowledging the influence of Darwin's theory of evolution in pragmatism and through pragmatism in occupational therapy is the basis of including the complex adaptive dynamical systems theory in this conceptual model. Complex adaptive dynamical systems theory is based on the notion of adaptation to the environment (Waldrop, 1992). Complex systems interact with the environment, reorganizing and continually emerging in new forms as they adapt to their environment. This notion seems to be a modern extension of the construct of adaptation that was central to Darwin's theory of evolution (Darwin, 1985). According to Darwin, species interact with the environment adaptively. Those that are able to evolve are able to adapt effectively and survive. Those that are not able to evolve become extinct. The complex dynamical adaptive systems theory adds the dimension of complexity to the construct of adaptation.

Above then, is the rationale for the choice of the historical literature of occupational therapy, the literature of the philosophy of pragmatism, and the complex dynamical adaptive systems theory as the sources of the theoretical core for the proposed conceptual model of practice. Details of the constructs/concepts chosen from the above sources, the theoretical core, and application of the model will be discussed in later papers.

Conclusion

The purpose of this paper was to present an argument for a new conceptual model of practice in occupational therapy which focuses on the mind as an instrument for human adaptation to the environment through occupational functioning. A literature review indicated that involvement of occupational therapy in mental health has declined significantly over time. The decline in occupational therapy involvement in mental health, combined with increasing emphasis of occupational therapy education and practice on understanding the medical aspects of clients with a seeming de emphasis on their occupational functioning, indicates a possible problem with professional identity.

It was argued that a conceptual model based on the pragmatic construct of instrumentalism, that emphasizes centrality of the mind in occupational functioning, would be in keeping with the historical origins and the philosophy of the profession. Such a model would help enhance professional identity. A diagrammatic illustration of the proposed model was presented and explained. A theoretical core of the conceptual model, the specific guidelines for practice, and recommendations for type II applied scientific inquiry to assess adequacy of the guidelines (Mosey, 1996), will be presented in subsequent papers.

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Socio-Emotionally Intelligent Development Politics

Towards a Framework for Socio-Emotionally Intelligent Development Politics: A Concept/Advocacy Paper*

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Abstract

This paper deplores the absence of socio-emotional capacity development content in traditional socio-economic development thought. It reviews arguments why the theme of socio-emotional well-being deserves to be acknowledged as a key contributor to human capital development. Next, the paper discusses conceptual frameworks and strategies for assisting planners and policy makers to include socio-emotional well-being into their socio-economic development strategies. The paper concludes with a framework proposal for planning socio-emotionally effective and sustainable development programs.

Introduction

Socio-emotional (or psychosocial) well-being is a prerequisite that enables children and adults to evolve into caring, non-violent, emotionally-healthy citizens (Staub, 2003). As globalization and social change have - in recent decades - led to increased levels of “socially constructed uncertainty” (Marris, 1991), there is concern that social support networks and care-taking relationships erode (UNDP, 1999), leaving behind “unhealthy” or “toxic” societies (Wilkinson, 1996; Garbarino, 1995; Vimpani, 2000).

Psychologists have called upon policy makers to foster and protect communities’ and nations’ social support network structures. A “Global Community Psychology” is needed, which - rather than strengthening therapeutic services - contributes through “envisioning, negotiating, designing and evaluating a humane

social order” (Marsella, 1999, p. 1289). “Reservoirs of care” must be preserved since “no vision becomes real, nor can it gain momentum, if there is not a main thread stitching together relationships at all levels of experience” (Independent Commission on Population and the Quality of Life [ICPQL], 1996, p. 115).

Notwithstanding, the theme of socio-emotional well-being presents a neglected building block in Third World socio-economic development discourse (Affolter, 2003). Although development agencies have abolished their rigid approaches of “economic growth through urban/rural industrialization”, and adapted instead “modernization” and “human capital development” frameworks (Peet & Hartwick, 1999), the theme of socio-emotional well-being - as a contributor to human capital development - remains un-discussed. LeVine (1983) observes:

[T]he logical connections between international development and child development - so transparently obvious . . . do not guarantee [a] rapprochement, either in science or in policy. One reason is that policy analysis in the international development field draws its concepts of human behavior largely from economics, in which formal utilitarian models of labor markets provide the primary basis for analyzing microsocial phenomena. In economic analysis, the processes of interest to child development research are more often relegated to the black box between aggregate inputs and outputs, or else they are ignored altogether. . . . (p. 45)

This paper seeks to close the disconnect between socio-economic development thought and socio-emotional well-being research. It advocates for an expanded human capital development notion that does not just seek to nurture sustained economic productivity (see UNDP, 1996), but also promotes - across communities and nations - the development of a caring, non-violent, optimally functioning citizenry (Staub, 2003). By this is meant the nurturance of people capable of fulfilling their basic psychological needs to a reasonable extent, in constructive rather than destructive ways, and who engage in continuously evolving series of experiences of effectiveness, identity and connection as a result of the continued fulfillment of these needs (Staub, personal communication, May 3rd, 2002).

The paper briefly summarizes insights from the fields of developmental psychology, social psychology and brain research that affirm the notion that human capital development is closely linked to socio-emotional well-being. Next, examples of frameworks and socio-emotionally conducive policies and development interventions will be reviewed. The paper concludes by proposing a conceptual framework for nurturing socio-emotionally healthy human ecologies, and psychosocial rehabilitation across communities and nations.

1. Review of the Literature: Human Development and Socio-Emotional Well-Being

“Caring” relationships between children and caretakers are - cross-culturally - a key ingredient for nurturing socio-emotional well-being. Although the cultivation of attachment ties may differ amongst cultures, the pursuit of proximity and protection, and suffering resulting from loss are universal phenomena (Valsiner, 1989; Rothbaum, Weisz, Pott, Miyake & Morelli, 2000, p. 1102; Eisenberg, 1992). Bretherton (1990; 1992) argues that transactional patterns evolve through initial child-caretaker interactions. They become internalized as mental working models, and eventually determine how an infant (child, adult) discusses attachment relationships with a third person (p. 237). Werner (1989) found that even vulnerable children (who suffered perinatal stress, chronic poverty, parents lacking education, troubling parental divorce experiences, discord, parental alcoholism or mental illness) eventually became successful adults, provided that their stressful lives were - during critical turning points - buffered and counterbalanced through protective social support network structures:

Competence, confidence and caring can flourish even under adverse circumstances, if young children encounter people in their lives who provide them with a secure basis for the development of trust, autonomy, and initiative. (p. 14)

Brain research confirms the conduciveness of socio-emotionally adequate support structures for physical, social and cognitive capacity development. Dobbing (1990) asserts that optimal brain development requires - beyond nutritional intake - emotional support:

Nutritional deprivation is only one element restricting normal child development, and it may even be a small one in relation to the other deprivations to which they are subject, except where malnutrition leads to serious infective illness, as it often does. Several examples were found of nutritional relief on its own, without adequate attention to “stimulation” in the environment, being without effect. Indeed there were even examples of “stimulation” alone producing apparent restoration to bodily, if not intellectual normality . . . , and, on the other hand, of undernutrition in an otherwise enriched environment not resulting in any detectable deficit at all . . . (p. 14)

Already during pregnancy, a mother’s physical and emotional well-being is crucial for the active promotion of optimal brain development of the fetus (Diamond & Hopson, 1998). Appropriate pre-school stimulation and nurturance is crucial for ensuring the realization of intellectual and social skills, particularly when considering that the “amygdala” (the part of the brain that manages emotional responses) grows and matures earlier than the cerebral cortex, and is very sensitive to parental feedback and handling:

An atmosphere conducive to healthy emotional development is probably the most important foundation a parent can provide. Proper nurturing at this stage is a priceless form of mental enrichment that lasts a lifetime, whereas inappropriate or inconsistent treatment, neglect, or outright abuse are forms of mental impoverishment that can also take a life-long toll . . .

Emotional development has a curious and important quality: As tiny infants, long before we have words to describe our feelings, our experiences with parents, siblings and caregivers - loving or harsh, supportive or destructive - help establish a mental map that will guide our emotional life, and, in turn, its influence on all of our thinking processes. (Diamond & Hopson, 1998, pp. 125-126)

Brain researchers today are able to explain how the “emotional mind” influences and dominates the “rational mind” (see Damasio, 1998; LeDoux, 1994). By controlling the endocrine system, whose hormonal outputs affect all bodily functions, the emotional brain affects the neocortex tone of symbolic activities such as language, strategic operations, and action planning. Thought is the product of the brain’s genetically specified wiring system, and past experiences of similar situations. Humans interpret reality in obedience to the dictates of their own emotions:

In the nervous system, information echoes down the filaments that join harmonious neural networks. When an emotional chord is struck, it stirs to life past memories of the same feeling.

One manifestation of these orchestral evocations is the immediate selectivity of emotional memory. Gleeful people automatically remember happy times, while a depressed person effortlessly recalls incidents of loss, desertion, and despair. Anxious people dwell on past threats; paranoia instills a retrospective preoccupation with situations of persecution. If an emotion is sufficiently powerful, it can quash opposing networks so completely that their content becomes inaccessible – blotting out discordant sections of the past. Within the confines of that person’s virtuality, those events didn’t happen. To an outside observer, he seems oblivious to the whole of his own history. Severely depressed people can “forget” their former, happier lives, and may vigorously deny them when prompted by well-meaning guardians of historical verity. Rage affords hatred an

upper hand that is likewise obtuse, sometimes allowing a person to attack with internal impunity those he has forgotten he loves. (Lewis, Amini & Lannon, 2000, p. 130)

Beyond the formation of attachment ties and relationship dynamics that impact dendritic growth and socio-emotional programming, macro-social structures facilitate or impede support networks' ability to stimulate socio-emotional well-being (see Folbre, 2001; UNDP, 1999; Kirby

Table 1. The Need for Positive Social Support Structures, and Developmental Consequences Across the Life-Span

Human Development	Developmental Psychology		Brain Development Research
Phase	<i>Western Developmental Psychology</i>	<i>Non-Western Developmental Psychology</i>	
Embryo-genesis	Psychological support prepares caretaker to effectively engage in child-parent relationship.	Women use pre-structured meaning systems provided by cultured environment for reasoning and adjusting to pregnancy.	Freedom from stress and "deliberate calmness" prevent possible damages in brain and nervous system.
Infancy	Caretakers' external feedback complements maturing forces of central nervous and internal feedback systems. Socio-emotional well-being of caretaker determines quality of child-parent interaction.	Non-Western cultures have alternative attachment procedures that may draw on infants' mothers only marginally, but instead draw on a variety of alternative resources available in the community.	Positive social stimulation produces bodily and intellectual normality. The emotional quality of social experiences determines the programming of the amygdala, and of the cerebral cortex of children.
Early Childhood	Affective communication with caretakers allows infants to develop and regulate their social interaction capabilities.	Affective communication, and processing of misunderstandings with adults and older siblings allows for the development of "cultured understanding".	Proper nurturing allows brain to establish mental map that will guide emotional life and thinking processes.
Middle Childhood	Multiple positive relationship opportunities (i.e. extended family) provide a rich data source for reflective experiential learning and the drawing of comparisons.	Children learn from emotional tones of adults and older siblings who frequently serve as their caretakers.	Structured leisure activities that elicit intrinsic motivation and high levels of attention produce continued branching/growing of dendritic trees.
Late Childhood	Nurturing, pro-social culture of parents and peers mold children's identity, behavior patterns, feeling of self-worth, as well as intellectual and social survival skills.	Kinship/informal education systems provide nurturance and guidance. Children become caretakers of younger siblings, thereby developing pro-social competence.	Same as above.
Adolescence	Through socio-emotionally competent caretakers, peers and prosocial bystanders, adolescents establish a sense of role and identity in life.	Different folk ideas harness different collective relationship experiences in terms of self-worth, social relationships and quest for meaning.	Structured leisure activities - "constructively connected to teens' emotional status quo" - produce continued branching/growing of dendritic trees.

Adulthood	Adults thrive in environments that make it possible to accommodate internal moral and mental attitudes with traditional values dictated by outer society.	Same.	Education, strenuous activity & active social life style increases and maintains mental agility, even among old people.
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Table 2. The Threat of “Toxic” Environments and Social Stress, and Developmental Consequences Across the Life Span

Human Development	Developmental Psychology		Brain Development Research
Phase	<i>Western Developmental Psychology</i>	Non-Western <i>Developmental Psychology</i>	
Embryo Genesis	Psychological discrimination enhances pre-partum depressions.	(No data available)	Anxiety releases stress hormones that damage dendritic trees.
Infancy	Poverty correlates with low maternal education, negative parental values and attitudes. Lack of social and economic support correlates with mental health problems and maternal anxiety.	Parents who have left behind traditional social support structures are vulnerable to various types of stress situations. Poverty may force women to intentionally neglect/abandon newborns.	Emotional deprivation inhibits bodily ability of self-restoration and development of intellectual normality.
Early Childhood	Anxious or insecure parents are inhibited in establishment of relationships with their own children. Single caretakers have limited resources to nurture the child or foster a reciprocal, responsive-sensitive relationship.	Life in “unplanned communities” deters caretakers’ attention from children towards economic production. Loss of pride and family separation leads to disoriented and deviant children and youth.	Harsh destructive relationship experiences establish mental map inspired by aggression rather than nurturance; and eventually guide future emotional & intellectual life.
Middle Childhood	Authoritarian / laissez-faire parenting prevents children from becoming effective agents in their own socialization, or to experience rational, issue-oriented cooperative interactions.	Life in communities separated from traditional kinship systems distances children from traditional values embraced by parents. Economic needs facilitate situations of child labor.	Families that are economically struggling, uneducated, emotionally distressed are less able to provide brain-stimulating environment.
Late Childhood	Negative regard from peers or parents correlates with negative self-worth, relationship problems and poor adjustment ability.	Social stress as a result of deteriorating levels of living, and communal disintegration creates anxiety spillovers.	Boring, uneducational, meaning-less instructive experiences fail to stimulate dendrite development.
Adolescence	Lack of socio-economic stability produces hostility. Lack of positive relationships results in feelings of alienation; resulting isolation may lead to the desire to commit suicide.	Socio-cultural changes and resource depletion leads to questioning of time-honored practices. Changes demand socio-emotional competence for responding and internalizing change.	Lack of meaningful relationships and learning environments results in failure to constructively address teenagers’ emotional “status quo”.

Adulthood	Unresolved tensions between inner moral and mental attitudes, and traditional values dictated by outer society create socio-emotional uneasiness.	Worries about food, housing, inability to satisfy children's physical needs leads to worries and anxiety, which have a pervasive effect on relationships and parenting quality.	Lack of socio-economic stability and meaningful, satisfactory social relationships decrease physical and emotional health.
Child Abuse	Physical, sexual and psychological trauma leads to psychiatric difficulties that show up in childhood, adolescence or adulthood.	Immigration, urbanization, changes from agrarian to urban economies, and alien social environments may increase potential maltreatment of children.	Stress affects brain's transmitters and leads to irrecoverable brain deformation.

& Frazer, 1997; Comer, 1989). Material inequality, for example, affects social relationships by imposing a psychological burden that reduces physical and emotional well-being (Wilkinson, 1996):

One of the ways in which adverse socio-economic circumstances may do lasting psychological and emotional damage is through increasing the levels of stress in which domestic life is lived. The social and economic environment establishes many of the difficulties with which domestic life has to cope and cannot be separated from a range of what are normally seen as family problems. It is not just worries about money, jobs and housing spill over into domestic conflict as tempers become more quickly frayed and parents find themselves with smaller reserves of patience and tolerance. It is also that lack of money, of choices, play space, the need for enough indoor space to accommodate incompatible family activities – in short, the lack of resources of all kinds (including time) – means that people's needs and demands are brought into conflict with each other. The tighter the constraints within which a family must operate, the fewer the dreams which can be satisfied, and the more people's interests conflict. The smaller the resources, the less the capacity to overcome unforeseen difficulties, accidents, breakages and losses. The greater the potential sources of stress and conflict, the more family life and social support will suffer. (pp. 163-164)

Economic, social and cultural challenges also stress well-established social systems in Non-Western societies. Globalization has led, on the one hand, to economic growth and spread of new technologies, but also, on the other hand, to social fragmentation, widening income disparities, job and income insecurity, financial volatility, threat of a worldwide recession, crime, the spread of HIV/Aids, as well as environmental degradation (UNDP, 1999). Globalization has uprooted traditional social support networks, sparking social morbidity and mass migration:

Deteriorating levels of living forced people to live in unplanned communities, witnessing how the environment became polluted, how community members suffered loss of pride for having become dependent on others rather than self sufficient, experiencing family separation and the generation gap, observing disoriented and deviant children and youth, watching the dying heritage of the past, seeing the misuse of leisure time, having sources of traditional foods neglected and feeling the mounting pressure of excess population. Such dimensions of social life and consciousness may very often be of much more importance in defining the quality of life as experienced by individuals, than are some of the factors more amenable to measurement and thus more attractive to policy makers. (MacPherson & Migdley, 1987, p. 76)

Table 3. *Modernity's Socio-Emotional Legacy*

Modernity	Developmental Psychology			
Features	<i>Socio-emotional consequences (West)</i>		Socio-emotional consequences (Non-West)	
	BENEFITS	RISKS	BENEFITS	RISKS
Values: individualism independence	Democracy, human rights, entrepreneurship, scientific achievement, economic growth.	Social “injustice”, ecologically unsustainable exploitation of the environment, social morbidity.	Perhaps human rights protection, benefit of technological achievements.	Colonization, dependency, socio-cultural deterioration and morbidity.
Economic beliefs: Free-market theory	Fosters entrepreneurial initiative and risk-taking; enhances material choices.	Unequal distribution of wealth, economic exclusion & discrimination; disruption of social support structures. Disregard for “social economy of well-being”.	Technological and financial input.	Socio-economic dependency. Unequal distribution of wealth; exploitation; disruption of social support structures and kinship ties.
Women's well-being	Inclusion in labor force creates economic independence and socio-political influence.	Double workload (care-taking and breadwinner). Socio-economic discrimination. Abuse.	Perhaps improved health. Women's rights. Child survival.	Socio-economic exploitation. Abuse. Women make up for dysfunctional support systems.
Family well-being	Nuclear families: More physical and social resources available for less children.	Lack of social support networks; social stresses make caretakers dysfunctional; violence, abuse, divorce.	Some selected families enjoy perhaps increased prosperity and material choices.	Migration and urbanization. Disruption of social kinship ties. Impoverishment. Inability to cope in new circumstances.
Child well-being	Improved physical health. Perhaps early childhood programs. Free primary school education. Children's rights.	Child neglect; violence, abuse.	Perhaps improved standards of health. Perhaps access to formal schooling and protection against abuse.	Child neglect and abuse. Child abandonment, labor, and prostitution.
Adolescent well-being	Improved school quality. Access to varied sources of stimulation.	Over-stimulation, lack of role models and meaningful relationships with caretakers; drugs, teenage pregnancy, school drop-out,	Access to various sources of stimulation. Perhaps access to educational opportunities and more health benefits.	Cultural and socio-economic changes are socially stressful and put squeeze on adolescent social support networks.

		social isolation.		
Adult well-being	Increased economic opportunities, choices, social security.	Increased competitiveness, social isolation, disruption of social support systems.	Perhaps more material choices, increased levels of health and material prosperity.	Economic pressures lead to socio-emotional exhaustion, break-up of kinship systems and social isolation.

Nobody knows how modernity, mobility, mass media, and industrialization will affect the “neural core of emotional identity” (Lewis, Amini & Lannon, 2000, p. 150). Yet, as change upsets social support mechanisms, it is likely to nurture a generation of perhaps educated, but psychosocially impoverished, and possibly dysfunctional, aggressive and violent citizens.

2. Towards a Framework for the Social Construction of Resiliency

Daniel Goleman (1995) has suggested that societies must psychologically “inoculate” (p. 247) children and leaders to handle emotional stress in an “intelligent” manner. Marris (1991) has advocated for social systems promoting socio-emotional resiliency, which “... minimize disruptive events, protect each child’s experience of attachment from harm, and support family coping” (p. 88). The challenge lies in the unfortunate dilemma that

Individuals and families are tempted to achieve certainty at the expense of others (i.e. by imposing a greater burden of uncertainty on them or by providing fewer material and social resources). When powerful groups in society promote their own control over life circumstances by subordinating and marginalizing others, they make it less possible for these groups to offer and experience security in their own families. (p. 88)

The following section presents “food for thought” for those development planners wishing to use socio-economic development interventions as a vehicle for “inoculating socio-emotional well-being”. It will:

1. Propose a map of social factors that influence - directly or indirectly - socio-emotional well-being. Visualizing and mapping out social contexts has the advantage of providing policy makers and development planners with an overview of key components affecting socio-emotional well-being.
2. Introduce Staub’s (2003) Taxonomy of Basic Human Needs. This taxonomy lists socio-emotional objectives to be pursued by policy makers and development planners interested in strengthening and protecting socio-emotional well-being.
3. Review policy recommendations, as well as practical examples of project interventions carried out in the past in order to enhance socio-emotional well-being and enablement - in the US as well as developing countries.
4. Propose a “Framework for Planning Socio-Emotionally Effective and Sustainable Development Programs”, which summarizes above mentioned concepts (#1-3), and serves as a checklist for guiding socio-emotionally “intelligent” development action.

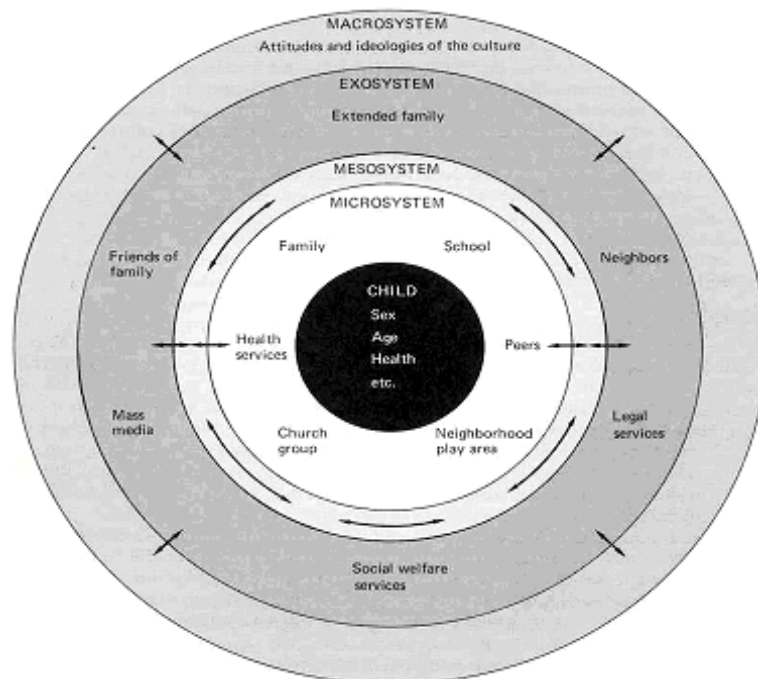
2.1. Socio-Emotional Well-Being and the Human Environment

Garbarino (1995) argues that policy makers must consider “the environmental balance of culture,

economies, politics, biology, and the psychological ebb and flow of day-to-day life” (p. 36) in order to appreciate how social systems shape socio-emotional well-being. As illustrated in Figure 1 (Garbarino, 1982, p. 648), a variety of factors affect well-being at the micro, meso, exo and macro-levels of the human ecology. Following Bronfenbrenner (1979), Garbarino describes them as follows:

Microsystem refers to relations between the child and the immediate environment; *mesosystem* refers to the network of interrelationships of settings in the child’s immediate environment; *exosystem* refers to social settings that affect the child but do not directly impinge upon him or her; and *macrosystem* refers to the attitudes, mores, beliefs, and ideologies of the culture. (Garbarino, 1982, p. 648)

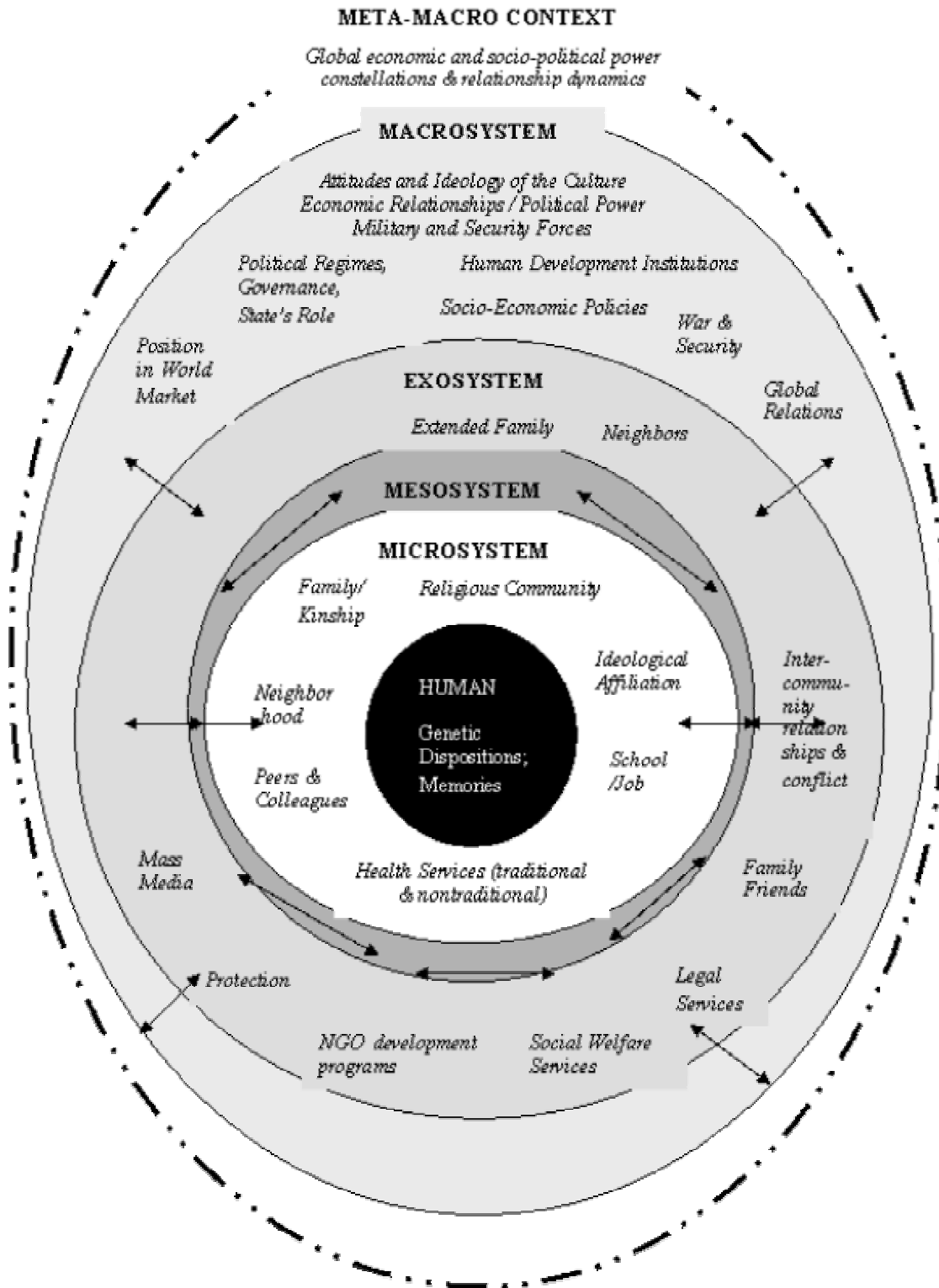
Figure 1. The Child in a Social Context

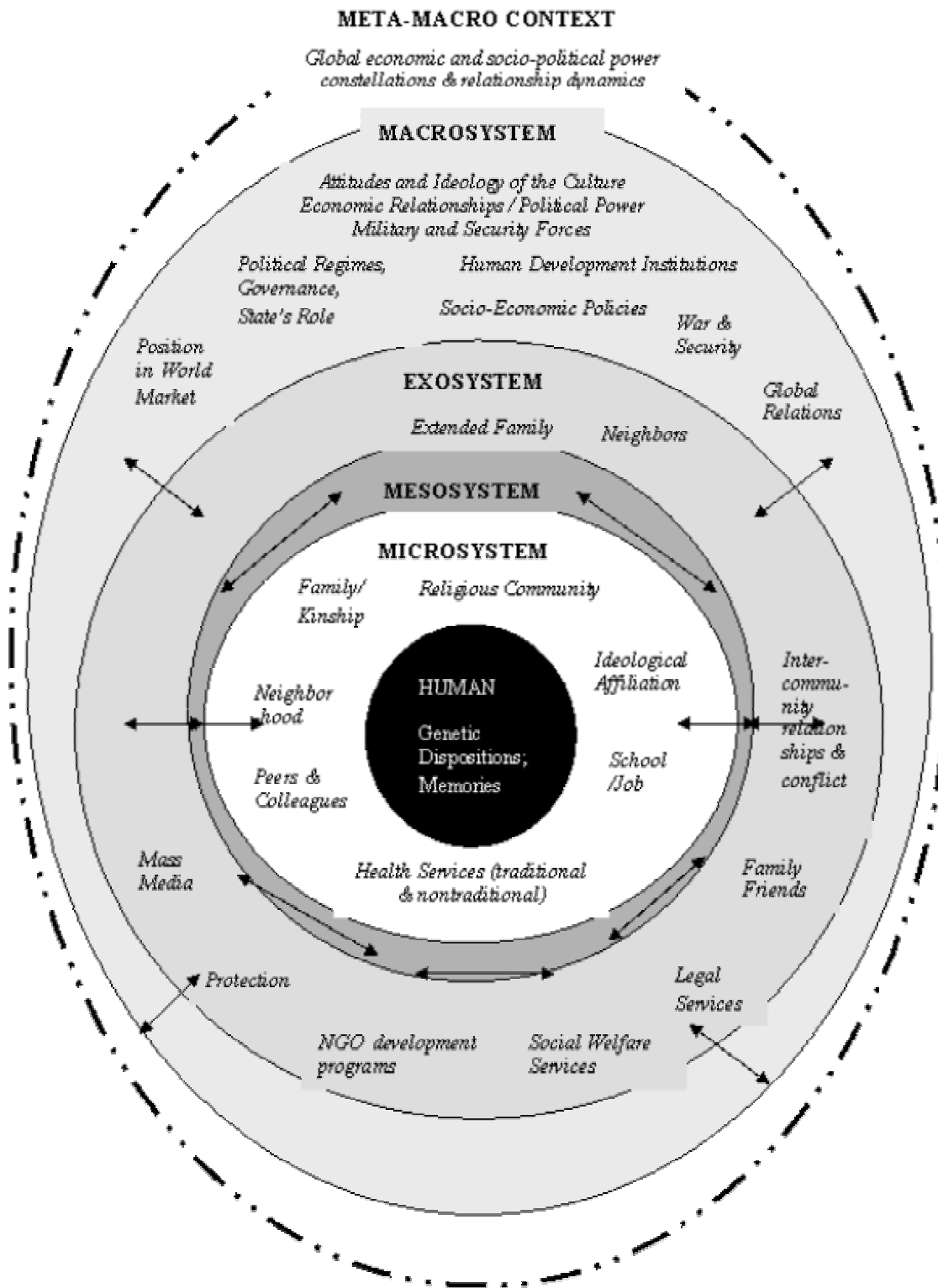


In order to benefit from Garbarino’s map for program planning in non-Western environments, it is necessary, however, to expand Garbarino’s design by including the socio-cultural and political particularities of the developing world. Figure 2 is an attempt to list those factors that shape socio-emotional well-being across cultures and nations. In addition, Figure 2 features an additional “meta-macro” eco-layer, in recognition of the fact that developing nations’ economic and civic stability, or misery, is a reflection not just of internal dynamics, but also of global political and economic power constellations.

Figure 2 provides a convenient map for policy makers and planners interested in identifying those social factors through which socio-emotional well-being can be stimulated.

Figure 2





2.2 Staub’s “Taxonomy of Basic Human Needs”

According to Staub (2003), the development of caring, non-violent and optimally functioning citizens depends on caretakers’ and societies’ ability to facilitate and sustain a long-term, well-balanced and constructive satisfaction of basic human needs, such as (a) security, (b) effectiveness and control, (c) positive sense of identity, (d) positive connection, (e) comprehension of reality, (f) independence or autonomy, (g) transcendence, and (h) long-term satisfaction (see Table 4). Staub’s taxonomy complements the map visualized in Figure 2, by providing a list of socio-emotional development objectives development planners should aim for when seeking to facilitate socio-emotional enablement and protection. According to Staub (2003), “security” is the most basic of all human needs. In addition, experiencing - on an ongoing basis - “effectiveness and control”, “positive identity”, “comprehension of reality”, “positive connection”, as well as “independence or autonomy” is necessary for engaging in social learning, and for choosing constructive means of basic needs satisfaction. Needs such as “transcendence” become progressively more important as life moves on; “long-term satisfaction” evolves with the prospect of being able to constructively satisfy of earlier-mentioned needs.

Staub claims that his taxonomy has cross-culturally validity. In other words, it does not matter whether one lives one’s life as a Bushman in the Kalahari dessert, or as a New York City citizen. The emotional need for feeling safe - i.e. freedom from physical and psychological threats - determines any person’s subjective well-being. At the same time, needs satisfaction strategies are culturally pre-determined. The satisfaction of needs such as “independence” and “positive connection”, for example, must match norms pertinent to a culture’s understanding of “legitimate independent behavior” or “culturally-valued behavioral expressions of social relatedness”. As such, any culture provides orientation, and permits experiences of independence

Table 4: Staub’s Taxonomy of Basic Human Needs

BASIC HUMAN NEED	RELEVANCE FOR SOCIO-EMOTIONAL WELL-BEING	ANTICIPATED PROCESS OUTCOMES
☐ Security	Experiences that foster the development of a sense of physical and psychological security, such that one considers oneself secure and protected against physical or psychological threats.	Self-confidence and desire for reaching out for positive relationships.
☐ Effectiveness and control	Opportunities to develop a sense of capacity for self-protection and goal achievement.	Enhanced self-esteem, trust in one’s own significance and desire to open up towards others.
☐ Positive Identity	Experiences that allow for the emergence of self-appreciation, self-awareness and desire to forge social relationships.	Positive outlook on one’s own (and consequently also others’) personal reality and being, as well as trust in capacity to transform oneself.
☐ Positive Connection	The ability to enjoy and draw energies from one’s contacts and relationships with other people or groups.	Readiness and openness for social interactions, and for supporting or contributing to the relationships (or the creation of relationships) of

<input type="checkbox"/> Comprehension of Reality	Development of an understanding of the world and its people (identities and functionalities).	others. Enhanced understanding on one's own purpose and role in life.
<input type="checkbox"/> Independence or Autonomy	Opportunities to take one's own initiatives, as well as to choose and select on one's own (feeling of being independent).	Enhances characteristics such as initiative, independence, perseverance and moral courage.
<input type="checkbox"/> Transcendence of the Self	Opportunity to relate oneself towards realities beyond one's current "personal reality" (e.g. nature, the arts, spirituality, social activism).	Opens people up to new forms of creativity, inspiration and mind-expansion. Makes people less likely to loose faith in the world and in oneself.
<input type="checkbox"/> Long-Term Satisfaction	Life context is such that people can develop confidence that there lies happiness and security ahead of oneself for the rest of one's life.	Enhances optimistic attitude towards future, desire to meet challenges, perseverance when facing obstacles.

or positive connection within fixed parameters of cultural propriety (see Raeff, 1997).

Staub's taxonomy of basic human needs can be used as a tool for facilitating policy makers' assessment of "landscapes of socio-emotional well-being" of individuals, communities, and perhaps nations. By monitoring and evaluating to what extent a development program enables caretakers and human ecologies to constructively and continuously satisfy basic human needs, policy makers will be able to devise development interventions that will strengthen what Wilkinson (1996) termed as the "Social Economy of Well-being" (p. 109).

2.3. Proposed Framework for Planning Socio-Emotionally Effective Development

The successful satisfaction of emotional needs requires socio-emotionally enabling environments at the micro, exo, macro and meta-macro level of human ecologies. This can be achieved through development interventions and policies that nurture family well-being and neighborhood safety; appreciation and respect for families within society (expressed in institutional policies and educational school curricula); strengthening natural helping networks; enacting governmental policies that promote tolerance and economic equity; and macro-political constellations that do not limit options for constructive emotional needs satisfaction within communities and societies around the globe.

Recommendations for efforts in the United States and Europe for strengthening families include diminishing economic disadvantages of families, discouraging divorce and out-of-wedlock childbearing, increase of parental earnings, and child and family tax exemptions (Hernandez, 1998). Families dealing with difficult stressful experiences require outside or governmental support. Schools could contain childcare and family outreach facilities, in order to counteract mental health disorders and other child development problems early-on. Industries ought to be obliged to grant flexible work schedules, part-time work opportunities, job-sharing, and parental leave policies for buffering stresses associated with work and family life (Zigler & Finn-Stevenson, 1999, pp. 568-569 & 571).

Early child education needs to be taken more seriously. Children's predisposition to learn, and the brain's growth spurts during the first ten years of children's lives implies the need for investing heavily in brain-

compatible, socio-emotionally conducive early childhood education (Abbott, 1999). Research and teaching on child and family socio-emotional well-being should be encouraged, and social scientists should be assisted in lobbying on behalf of children and families (Zigler & Finn-Stevenson, 1999).

Governments' policies must commit to an atmosphere of social tolerance, which, in turn, nurtures security and socio-emotional well-being (Wilkinson, 1996). A "Report on the Social Health of the Nation" might be an effective mechanism for affecting the social rhetoric and consciousness of governments and political elites (Miringoff & Miringoff, 1999).

In the international arena, Levinger (1996) proposes to strengthen communities by cultivating family life, aid for earning of a livelihood, harnessing environmental stewardship, and the promotion of civil society. For Levinger, socio-economic survival in the 21st century depends to a large measure on opportunities to cultivate people's prosocial and networking skills. Bartlett, Hart, Satterthwaite, de la Barra and Missair (1999) recommend launching institutional capacity development programs for municipal authorities for conducting child and family-conducive project activities at the exo-level.

Beyond national policy initiatives, it will be necessary to institutionalize international trade accords, and to integrate agreements on human rights and environmental protection, in order to make global trade socially and ecologically sustainable. Corporations could and should pay minimum tax in order to financially compensate for their host countries' investments in the development of human and social capital now harvested by foreign companies. International debt could be forgiven, and the granting of new credits could be made dependent on governments' commitment to push social policy agendas - such as girls' education - in areas under their jurisdiction (Folbre, 2001).

As far as post-conflict societies are concerned, programs ought to facilitate reconciliation and "friendly relationships" among groups with histories of recent conflict. Connection-building processes are needed, where members of estranged groups share and engage in planning activities towards common goals. Leadership interaction in politics, business, education and science need to receive active support from the international community, as do institutions that encourage cross-border group initiatives and positive bystandership (Staub, 1989). Agencies should also consider therapeutic interventions for children and adults suffering from trauma as a result of experiences of extreme violence (Staub, 1999; Maynard, 1999).

The section that follows introduces a number of initiatives that have converted above-mentioned policy recommendations into concrete development practice:

2.3.1. US and International Examples for Strengthening Social at the Micro-Level

In the US, early childhood education programs such as HeadStart have effectively fortified self-esteem and development of language and pre-reading skills in the classroom. The "School of the 21st Century" gained popularity for using school as a coordinating base for childcare and family support services. Community school initiatives advocate for improved student achievement by means of increased communication between school staff and parents, and by fostering positive relationships (Zigler & Finn-Stevenson, 1999).

A variety of schools have successfully implemented courses for socio-emotional capacity development (see Goleman, 1995, for an overview of evaluation results). The Northeast Foundation for Children has developed a classroom management approach that fosters self-control, social participation and human development by teaching children self-control, self-discipline, as well as caring for oneself, one another, and the world (Charney, 1991). Kessler (2000) has developed a curriculum that helps adolescents to find deep connection, silence and solitude, meaning and purpose, as well as joy, delight, creativity and transcendence within school. The Association for Supervision and Curriculum Development [ASCD] has published guidelines for psychosocial capacity development that assist US teachers interested in promoting social and

emotional learning in American schools (see Elias, et al., 1997).

Internationally, programs such as the Nueva Escuela program in Columbia (Schiefelbein, 1991), the BRAC Rural Primary School system in Bangla Desh (Lovell & Fatema, 1991), the Upper Egypt Community Schools (Hartwell, 1997) and the Child Scope Project in Ghana (Miller & Pittman, 1997) have taken specific steps to enhance culturally relevant learning in a determined context. UNICEF has used school curricula for addressing topics such as children's rights and peace education (Fountain, 1999). A successful example of "school as community space" is the "Centro des Formacao do Educador Popular Maria da Conceicao" in Recife, Brazil, which simultaneously serves as a pre-school, day care center, primary school, professional training center and community meeting place (Bartlett, Hart, Satterthwaite, de la Barra & Missair, 1999, p. 166).

2.3.2. US and International Examples for Social Support Initiatives at the Exo-Level

In the United States, needy families receive financial assistance through the TANF [Temporary Assistance for Needy Families] Program (Folbre, 2001). Training programs for mothers who have experienced abuse in their own childhood were successful in initiating non-abusive relationships with their own infants, provided that the interventions were carried out prior to an infant's birth (Staub, personal communication, October 2000). Since disadvantaged children and families may need intensive treatments for counteracting the pervasive effects of poverty, violence, social dislocation, and other inner-city childhood experiences, some agencies have launched "two-generation projects" that help children to get the best possible start in life, and parents to become economically self-sufficient (St.Pierre, Layzer & Barnes, 1998).

Riley (1997) has documented how the University of Wisconsin community extension program effectively influenced community psychological well-being by engaging communities in locally-conducted socio-emotional community research. A psycho-educational training program in Florida succeeded in facilitating attitudinal changes amongst citizens of a marginalized inner-city community in Modello (Pransky, 1998). As participants overcame psychopathological dysfunctions, they launched community mobilization programs that gradually transformed the socio-economic status quo of Modello.

Development interventions that use participatory community development approaches at the grassroots level are likely to socio-emotionally empower immediate project beneficiaries. Sebstadt & Chen (1996), for example, in their meta-analysis of women micro-enterprise evaluation reports from Asia, Africa and Latin America, found that micro-enterprise initiatives led to increased self-confidence amongst African women. The Barefoot College in Tilona, India (Barefoot College, 2000) has earned international admiration for creating a learning and community environment where activities are chosen, planned, implemented and evaluated by community members themselves. In Tilona, learning by doing in a meaningful context allowed for intense inductive learning to occur, which, in turn, impacted mind, attitudes and emotions.

Socio-emotional enablement can also be enhanced amongst children and adults by mobilizing rural communities to become the patrons of their own community schools, thereby enhancing social cohesion at the local level (see Hartwell, 1997). In Bolivia, Universidad Núr developed a series of educational leadership manuals, based on a framework that fuses development of social capacities with development learning and community mobilization knowledge (Anello, 1997). Around the world, NGOs have experimented with the so-called "children teaching children" approach, where children participate in the planning and execution of development programs, and serve as trainers or mentors to other child members of the community (Hart, 1997).

In crisis and emergency situations, peace and human rights education programs, programs to reintegrate child soldiers, as well as specific therapeutic assistance for traumatized populations are increasingly used as avenues to provide psychosocial emergency assistance (Affolter & Miller, 2002). A human rights education

initiative in Peru that trained 900 community leaders from across the country in human rights, democracy, and citizen participation was particularly well-received amongst women: women participants reported that it improved the communication amongst their own family members, that it motivated them to protect their own rights, and that it stabilized their position as leaders in their communities. Another outcome was a decrease of physical violence (Bernbaum, 1999). In Rwanda, a psycho-educational training on healing and reconciliation for Hutu and Tutsi community mobilizers reduced participants' level of war trauma, while increasing a positive orientation by Tutsis towards Hutus (Staub & Pearlman, 2003).

Bartlett, Hart, Satterthwaite, de la Barra and Missair (1999) have argued that the use of the Convention of the Rights of the Child - as a framework for guiding development interventions - could inspire ecologically sensitive child development initiatives. Efforts to promote the rights of the child automatically imply strengthening the social support structures in children's immediate environment, and thus are beneficial even to the socio-economic as well as socio-emotional needs of adult caretakers. Child well-being as a development agenda also serves as a unifying power amongst groups with histories of conflict (see Menary, 1990; Reimers & McGinn, 1997).

2.3.3. Macro and Meta-Macro Examples

There are few documented examples of initiatives that strengthen social support networks at the macro-policy level. One is undoubtedly the welfare systems of some northern European states who finance extended periods of child-leave opportunities for employed parents (UNDP, 1999). Another example is the United States Congress' initiative to funnel funds into selected, economically depressed urban and rural "Empowerment Zones", combining individual and family-centered services with social and economic initiatives (Wright, 2001).

The Government of Venezuela created, in the 1970s, a Ministry of Human Intelligence with the mission to nurture a *culture of thoughtfulness* for fostering mental management, and systemic thinking (Perkins, 1995, p. 207). This initiative no longer exists, however.

At the meta-macro level, the most prominent example for strengthening and protecting children's socio-emotional well-being is the Convention on the Rights of the Child, which has been ratified by almost all World Governments. International research programs such as an initiative entitled "Learning to Hate, Learning to Care" (funded by UNESCO) (Ohsako, personal communication, May 2002) have the potential to develop a deeper cross-cultural understanding into the roots of helping and altruistic behavior, as well as individual and group violence.

2.4. A Policy and Planning Framework for the Social Construction of Resiliency

Table 5 summarizes strategies that could facilitate the constructive satisfaction of basic human needs, thereby strengthening "reservoirs of care" - across cultures and nations. What remains to be emphasized is a need for *complementary* socio-emotional support initiatives launched *simultaneously* at multiple levels of the human ecology!

Not all development agencies have the capacity (or the clout) to sponsor or to advocate for socio-emotional rehabilitation initiatives at local, regional, national and international levels.

Multilateral agencies such as the World Bank, or the United Nations, however, are in a position and do have the means to provide socio-emotionally enlightened policy advice to governments around the world, and to integrate socio-emotional rehabilitation strategies into their overall strategic plans. Not only that: they could monitor and evaluate traditional socio-economic development interventions not just for economic

productivity, or compatibility with the Human Development Index, but also for their conduciveness to strengthening socio-emotional well-being, and protecting social support networks.

Table 5: Proposed Framework for Planning Socio-Emotionally Effective and Sustainable Development Programs¹

META-MACRO CONTEXT	MACRO CONTEXT	EXO-CONTEXT	MICRO-CONTEXT	NEEDS TO BE SATISFIED	DESIRED OUTCOMES
<ul style="list-style-type: none"> • International agreements that make institutionalization of international trade accords dependent on <ul style="list-style-type: none"> ▪ Protection of workers' /children's) rights; ▪ Environmental protection. • "Forgiveness" of debts coupled with requirement for pro-social policies. • International system of governance in which poor countries have same representation as rich countries, which would allow for <ul style="list-style-type: none"> ▪ Penalization of countries that refuse to guarantee basic democratic rights or environmental protection by restricting access to consumer markets; ▪ Imposition of minimum rule of taxation for corporations within developing countries. 	<ul style="list-style-type: none"> • Economic policies that <ul style="list-style-type: none"> ▪ decrease income differences and enhances economic equity; ▪ provide tax incentives and financial rewards for care-takers. • Policies/governance that harnesses social tolerance and justice-oriented values in favor of women, parents, disadvantaged classes, races, and citizens with health deficits (through business, labor, welfare, media, educational policies). • Governmental and multilateral development agencies' support for municipal and NGO institutional capacity and advocacy development, for the development of projects and interventions in the areas of child support, family support, women support, and reconciliation. • In situations of conflict, governmental and development agencies' support for social reconstruction, "friendly relationships", and healing. • Government provides family-sensitive sustainable welfare support. • Government monitors and reports on "Social Health of the Nation". 	<ul style="list-style-type: none"> • Opportunities for education & employment. • Care-taker -friendly employment policies. • Civic rights. • Extended reciprocal network of family members friends. • Socio-economic security. • Municipal programs supporting child, family and women well-being. • Municipal programs towards reconciliation, friendly relationships, and healing. 	<ul style="list-style-type: none"> • Nutritional security and adequate housing. • Harmonious, predictable, affectionate & reciprocal relationships within family and kinship structures. • Harmonious & reciprocal community structures. • Harmonious reciprocal school culture. • Harmonious & reciprocal peer relation-ship structures. • Prosocial media messages. 	<ul style="list-style-type: none"> • Security • Effectiveness and Control • Positive Identity • Comprehension of reality • Positive Connection • Independence or Autonomy • Long-term satisfaction • Transcendence 	<ul style="list-style-type: none"> • Citizenry that is <ul style="list-style-type: none"> • Caring • Non-violent • Optimally functioning

Another important prerequisite for enhancing the effectiveness of socio-emotional program interventions is *continuity*. Bronfenbrenner & Morris (1998) define Human Development as "stability

¹ Garbarino's (1982) "meso-dimension" is not included in this table. It refers to the overall compatibility of micro, exo and macro structures and can as such be considered by development planners seeking to implement socio-emotionally effective development programs.

and change in the bio-psychological characteristics of human beings across successive generations” (p. 995). For development to occur, a person must engage in activity on a fairly regular basis and over an extended period of time. Activities need to become increasingly more complex, and involve reciprocal exchange with people, objects and symbols in ways that attention, exploration, manipulation, elaboration and imagination become a possibility (pp. 996-997). As a result, socio-emotional well-being cannot be positively affected through brief project “injections”, as it often occurs in socio-economic development practice. Instead, systems need to be established that maintain their socio-emotionally nurturing quality over an extended period of time. Multilateral agencies need to prepare policies and programs that provide a constructive and long-term approach to satisfying basic human needs.

Conclusion

Traditional socio-economic development discourse is void of discussions and strategies for strengthening and rehabilitating socio-emotional well-being. If not endowed with a specific child development or human rights agenda, development agencies prefer to focus on economic growth, education and health as a means to contribute to the overall goal of human prosperity. Notwithstanding, socio-emotional well-being or distress has implications for the sustainability of socio-economic development programs. As Wilkinson (1996) states:

To feel depressed, cheated, bitter, desperate, vulnerable, frightened, angry, worried about debts or job and housing insecurity; to feel devalued, useless, helpless, uncared for, hopeless, isolated, anxious, and a failure; these feelings can dominate people’s whole experience of life, coloring their experience of everything else. It is the chronic stress arising from feelings like these, which does the damage. It is the social feelings that matter, not exposure to a supposedly toxic material environment. The material environment is merely the indelible mark and constant reminder of the oppressive fact of one’s failure, of the atrophy of any sense of having a place in a community, and of one’s social exclusion and devaluation as a human being. (p. 215)

Socio-economic development planners must accept responsibility to participate with their resources and positions of influence in working towards the socio-emotional rehabilitation and protection of communities, societies and nations. Any type of social action, whether carried out by a caretaker, by communities, or by politicians and business leaders eventually ripples through the ecology of humankind’s interrelatedness, stifling or enhancing care-taking relationships and human capital development. The challenge of the years ahead consists not only in increasing and sustaining economic productivity; there also is a need to decrease “socially-constructed uncertainty”, by protecting and strengthening social support networks as key contributors to socio-emotional well-being. Material and socio-emotional needs must be addressed jointly, so that they positively reinforce one another.

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Evaluation of Integrated Treatment Outcomes at Places for People

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Abstract

The problem of co-occurring mental health and substance use disorders is one of the most intractable challenges facing mental health treatment systems. Individuals with dual diagnosis have lower levels of functioning and poorer life outcomes in a broad range of areas. Treatment providers have gone from parallel and sequential forms of treatment to an integrated model. Places for People, Inc., a mental health agency in St. Louis, implemented an integrated treatment program in 2001. This study examines outcomes of this program.

Demographic and outcomes data were collected on a sample of 31 clients. Three of the 6 outcome measures were found to have statistical significance: Global Assessment of Functioning score, substance abuse/dual hospitalization rate, and housing status. Participation in the integrated treatment program is associated with some positive change in life outcomes. Though it is not possible to say for certain whether these gains were caused by the program, the results are nonetheless encouraging.

Introduction

The problem of patients who are dually diagnosed with substance use disorders and severe mental illness is one of the most persistent challenges in the mental health field. Individuals with dual diagnoses consume more treatment resources (Drake, et. al., 1996), have more frequent hospitalizations, have more trouble caring for themselves, and exhibit more disruptive behaviors in the community than individuals with a diagnosis of only serious mental illness (Drake & Wallach, 1989).

Dual diagnosis is also more common than was once thought. Thirty-seven percent of those who abuse alcohol and 53 percent of those who abuse drugs also meet diagnostic criteria for at least one severe mental illness (NMHA, 2003).

For decades, the standard of treatment for dual diagnosis was parallel treatment. The dually diagnosed person would receive separate substance abuse services and mental health services, often from two separate agencies, and would be responsible him/herself for integrating the services and information received from each (Drake, et. al., 1996). The other common scenario was sequential treatment, in which the person with the dual diagnosis would be treated by one service system, and then discharged to be treated by the other system, with no communication or interplay between the mental health and substance abuse agencies (Mueser, et. al., 2003). More and more, however, the standard of care has become integrated treatment, whereby substance abuse and mental health services are delivered under the same roof, by the same clinicians, as one package of services (Drake, McHugo, et. al., 1998). Reviews have been conducted on the effectiveness of integrated treatment, and the consensus seems to be that integrated treatment is more effective than parallel or sequential treatment for individuals with dual diagnosis (Drake, Mercer-McFadden, et. al., 1998).

Despite the fact that integrated treatment seems to be the method of choice for intervention with dually-diagnosed individuals, according to the Substance Abuse and Mental Health Services Administration (SAMHSA), there is still lacking a strong evidence base for which kinds of integrated interventions work the best (SAMHSA, 2003). Case management, group therapy, and individualized motivational techniques all show promise (Drake, McHugo, et. al., 1998; Ridgely & Jerrell, 1996). Also of interest are blends of these methodologies. More research is needed in order to understand which programs and combinations of programs lead to improved outcomes with this population.

Through this study, the author hopes to add to the evidence base regarding effective interventions for clients with co-occurring disorders.

This purpose will be carried out through the following objectives:

1. To describe the integrated treatment program at Places for People, Inc.
2. To analyze demographic and outcomes data from 31 client charts and the Places for People management outcomes database.
3. To learn from this analysis whether the Places for People integrated treatment program is associated with improved outcomes.

Places for People, Inc. is a small mental health agency located in the Central West End neighborhood of St. Louis, Missouri. The agency was founded in the early 1970s in response to the de-institutionalization of many people with mental illness who had spent much of their lives in state hospitals (Places for People, 2003a). In the 1990s, the population served by the agency began to shift to include more people with mental illness who were younger and who were often homeless (Places for People, 2003b). The integrated treatment program at Places for People, Inc. was started in the fall of 2001. Agency leaders recognized that the problem of co-occurring disorders was becoming more and more prevalent, and in early 2001, the position of Integrated Treatment Specialist was created. An MSW-degreed staff person from within the agency was hired to fill the position, and the program developed under his leadership.

Integrated treatment at Places for People consists of several different components. One is intensive case management. Places for People operates five continuous treatment teams, all of which serve homeless and

dually-diagnosed individuals. One clinical team, the HOME team, specializes in outreach and engagement with clients who are homeless or in unstable housing situations. All clinical teams have received training in harm reduction (Marlatt, 1998) and motivational interviewing (Miller & Rollnick, 2002). The integrated treatment specialist consults with members of each continuous treatment team to help assess what kinds of interventions might be most helpful to particular clients.

Another aspect of the integrated treatment program consists of group interventions. Groups for dually-diagnosed clients meet seven days a week at Places for People. Five days a week, the integrated treatment specialist coordinates the groups, which include Double Trouble, Dual Recovery Anonymous, cognitive-behavioral therapy, and “persuasion” (Mueser, et. al., 2003) groups. On the weekends, the integrated treatment groups are peer-led.

The program also provides social support. Several times a week, following their group meeting, members of the integrated treatment program go to a neighborhood coffeehouse to play pool and air hockey, drink coffee, and support one another. Places for People has budgeted funds to pay for the first beverage of the day for every participant.

Places for People also offers payeeship services, nursing services, and a psychosocial rehabilitation program to all of its clients. A “damp” housing development (Mueser, et. al., 2003) is under construction .

Harm reduction is an essential theme in all of Places for People’s services. The integrated treatment program aims first to reduce the negative consequences created by substance use behaviors, and then works with each individual to develop the motivation to change those behaviors (Marlatt, 1998; DiClemente, 2003).

Six outcome measures of the integrated treatment program will be examined: Global Assessment of Functioning scores; psychiatric hospitalizations; substance abuse/dual hospitalizations; medical hospitalizations; housing status; and arrest rates.

The hypotheses that are being tested are as follows:

- Global Assessment of Functioning (American Psychiatric Association, 2000) scores will increase from the year before program implementation to the year after its implementation. This is because reduced substance use and stabilization of psychiatric symptoms will lead to gains in levels of functioning.
- Psychiatric hospitalizations will decrease from the year before to the year after because involvement in treatment will help to mitigate psychiatric symptoms.
- Substance abuse/dual hospitalizations will increase as more clients enter the action stage of readiness to change (DiClemente, 2003).
- Medical hospitalizations will decrease as clients gain greater medical stability.
- Fewer clients will be homeless or housed in hotels during the second year examined when compared to the first year examined.
- There will be fewer arrests in the second year than in the first year, as clients reduce their substance use and therefore become less likely to commit crimes

This study has limitations that restrict the ability of its results to be generalized to other programs and

settings. First of all, the sample size (N=31) is very small, making the results less dependable. In order to obtain consistency in the time period studied, it was necessary to include only clients who began the dual diagnosis program in November, 2001. The integrated treatment program has actually enrolled over 80 clients during the past two years.

In the sample of dually-diagnosed clients whose records were reviewed for this study, less than one-fourth of the subjects were women. This makes generalizing the results of this study to the experience of women with co-occurring disorders difficult.

Another limitation is that detailed demographic data for Places for People's clientele as a whole is unavailable at this time, making it difficult to know whether the differences between the integrated treatment sample and the entire agency's population are statistically significant.

In addition, it is, of course, impossible to say for certain whether the improvements and setbacks noted in this study are caused by the clients' enrollment in integrated treatment, or whether these events should be attributed to some other aspect of their lives or involvement with Places for People.

Materials and Methods

Data for this study were obtained from the Management Outcomes database and from the clients' medical records at Places for People, Inc. The sample was selected from the roster of Places for People clients who have participated in intensive case management since November, 2000 or before, and who began the integrated treatment program in November, 2001. This yielded a sample size of 31. Each subject in the sample possessed a diagnosis of severe and persistent mental illness as defined by the Missouri Department of Mental Health as well as a diagnosis of substance abuse or dependence.

The author was granted a waiver of informed consent by the University of Missouri-Columbia Health Sciences Institutional Review Board for the clients in this study on the condition that the names of study participants not be available to her. Therefore, in December, 2003, the Medical Records Manager and the Clinical Director of Places for People extracted the data from the client charts and the Management Outcomes database and created a spreadsheet of client information, assigning a number to each client in the sample. The following descriptive information was collected: age, gender, and ethnicity of each client. Information about the sample of dual diagnosis clients was compared to demographic information reported in the Fiscal Year 2002 Management Report of Places for People (Places for People, 2002).

Six different outcome measures were collected. These were Global Assessment of Functioning (GAF) scores; number of psychiatric, substance abuse/dual diagnosis, and medical hospitalizations; housing status; and number of arrests. GAF scores and housing status were assessed for November, 2001 and November, 2002. Hospital admissions and arrest rates were measured for the period from November, 2000 to October, 2001 and from November, 2001 to October, 2002. In this way, outcomes for the year prior to the start of the integrated treatment program could be compared to outcomes for the first year of the program's operation. Selected outcomes were chosen largely because these pieces of information were readily available in client charts and the Management Outcomes database. An outcome related to reduction in substance use was not chosen because Places for People does not put initial emphasis on this outcome. The harm reduction approach that Places for People uses makes improvement in housing status and GAF, plus reduction in arrests and hospitalizations, more important than reduction in overall use of substances.

Data for this study were analyzed using SPSS 9.0 for Windows. In analyzing the outcomes data, paired-samples t-tests were performed.

Approval from the Health Sciences Institutional Review Board of the University of Missouri-Columbia was granted on September 15, 2003. A waiver of HIPAA authorizations was granted on July 15, 2003. This protocol was found to be of minimal risk to the research subjects. The author of this paper is employed by

Places for People but works in its residential program rather than in the integrated treatment program.

Results

The following demographic information was collected about the 31 clients in the sample: age, gender, and ethnicity. The results are as follows:

- The oldest client in the sample was 56 years old.
- The youngest client was 30 years old.
- The average age was 42 years.
- The standard deviation was 6.94.

The Fiscal Year 2002 management report of Places for People states that the average age of its clients is 47, with an age range of 20 to 83 (Places for People, 2002). Clients in dual diagnosis treatment were somewhat younger than the clients of the agency in general.

Gender

- 24 clients were male. (70.8%)
- 7 clients were female. (29.2%)
- Males outnumbered females by more than 3 to 1.

Places for People as a whole had 45.7% female African-American and European-American clients and 53.5% male African-American and European-American clients in fiscal year 2002 (Places for People, 2002).

Ethnicity

- 18 clients were African-American. (58.1%)
- 13 clients were European-American. (41.9%)

This reflects a higher percentage of African-American clients than in the agency as a whole. According to the Fiscal Year 2002 management report of Places for People, 42.9% of the agency's clients were African-American, and 56.4% were European-American (Places for People, 2002).

Outcome Measures

Summary of Outcome Measures

The tables below provide a summary of information regarding the six outcome measures. Measures that represent a point in time are in Table 1, and measures that tallied occurrences over a period of time are in Table 2.

Table 1: Outcome Measures

Outcome	Mean, 11/01	Standard Deviation, 11/01	Mean, 11/02	Standard Deviation, 11/02	p value
Global Assessment of Functioning	41.06	7.34	43.71	6.30	.048
Housing	.23 (23% of the sample was homeless in 11/01)	n/a	.00 (No clients in the sample were homeless in 11/02)	n/a	.006

Table 2: Outcome Measures, Continued

Outcome	Mean, 11/00-10/01	Standard Deviation, 11/00-10/01	Mean, 11/01-10/02	Standard Deviation, 11/01-10/02	p value
Psychiatric admissions	.81	1.60	2.06	5.18	.166
Substance abuse/dual admissions	2.16	.3.09	.71	1.07	.011
Medical admissions	.32	1.45	.01	.40	.415
Arrests	.29	.59	.29	.82	1.000

Global Assessment of Functioning

Global Assessment of Functioning scores were examined twice, once in November, 2001, when the integrated treatment program began; and again in November, 2002, after the program had been operational for a year.

It was found that the difference in GAF scores from November 2001 to November 2002 was statistically significant ($p=0.048$). The range for both time periods was 25, with the highest score being 55 and the lowest 30. The highest and lowest scores did not change, but those in the middle of the range were slightly higher. It is interesting to note that the average GAF score during both periods represented a level of functioning so impaired as to necessitate inpatient treatment in many cases (Dziegielewski, 2002). This sample did experience quite a few psychiatric and dual-diagnosis hospitalizations, but it is surprising, perhaps, that there were not more.

Housing Status

Housing status for the 31 clients in the sample was compared from November, 2001 to November, 2002. Clients were divided into two groups: those who were homeless or living in a hotel; and those who were living independently, with family/friends, or in a residential care facility. Seven clients were homeless or living in a hotel in 11/01.

- There were no clients in 11/02 who were homeless or living in a hotel.
- This difference is statistically significant ($p=.006$).

Psychiatric Admissions

Inpatient admissions were tallied for the twelve months before the integrated treatment program began, and for the twelve months after the program's inception. The mean number of psychiatric hospitalizations per client for the period of 11/00 to 10/01 was 0.81. The mean for the period of 11/01 to 10/02 was 2.06 hospitalizations per client.

This is a startling increase from one year to the next; however, it is not statistically significant ($p=0.166$). Part of the increase from one year to the next can be attributed to one particular client who had 27 psychiatric inpatient admissions from 11/01-10/02. The largest number of psychiatric hospitalizations that any one client had in the previous time period was eight.

Substance Abuse/Dual Hospitalizations

Substance abuse and dual hospitalizations were counted for the same time period as psychiatric hospitalizations: November 2000 to October 2001; and November 2001 to October 2002. The mean number

of hospitalizations during the first time period was 2.16 per client; during the second time period, this number had decreased to 0.71. The decrease in substance abuse/dual inpatient hospitalizations from one year to the next was found to be statistically significant ($p=.011$). Broderick (personal communication, December 20, 2003) has commented that substance abuse/dual hospitalizations may have decreased because clients were no longer needing to escape their situation or hide from someone to whom they owed money.

Medical Hospitalizations

Inpatient medical admissions were also counted for the year before the integrated treatment began and for the first year of the program's operation. There were very few medical hospitalizations among the 31 clients, making data analysis difficult. The total number of medical admissions from 11/00-10/01 was ten; from 11/01-10/02, the number was three. Analysis of the data showed that although there was a decrease in medical admissions, the difference was not statistically significant ($p=.415$).

Arrests

Data on arrests were collected from November 2000 to October 2001 and from November 2001 to October 2002. There were a small number of occurrences of arrests during both time periods.

- Seven clients were arrested from 11/00-10/01 for a total of nine arrests.
- Five clients were arrested from 11/01-10/02 for a total of ten arrests.
- This difference is not statistically significant ($p=1.000$).
- The standard deviation for the first time period was 0.59; for the second period it was .82.

Discussion

Summary

A review of the literature on dual diagnosis treatment shows that integrated treatment programs are favored over parallel and sequential treatment modalities (Drake, Mercer-McFadden, et. al., 1998). The Places for People program contains several elements of programs that have been shown to be successful (Mueser, et. al., 2003). These include intensive case management, outpatient group interventions, and social support.

This project revealed that participation in Places for People, Inc.'s integrated treatment program is associated with several changes in client outcomes. Global Assessment of Functioning scores increased significantly, as was hypothesized. Housing status improved significantly, as none of the 31 participants were homeless or in a hotel at the end of the program's first year. And, opposite of what was hypothesized, substance abuse/dual diagnosis hospitalizations decreased significantly.

There were several outcomes that were not associated with significant change. Psychiatric hospitalizations increased from the year before the program's genesis to the first year of its implementation. The arrest rate stayed the same from one year to the next, and though medical hospitalizations decreased from one period to the next, the difference was not significant.

Conclusions

The Places for People integrated treatment program appears to be associated with some positive changes for its participants. The program participants show a great deal of affection toward the Integrated Treatment Specialist, and according to the Integrated Treatment Specialist, the clients find their participation enjoyable and beneficial (A. J. Nave, personal communication, December 30, 2003). Though it cannot be said that the integrated treatment program caused these positive changes, the association is important. As change in dually-diagnosed clients must be measured in years rather than months or days, the program should continue, striving to increase its fidelity with the evidence-based integrated treatment model, and collecting more and better outcome and demographic data (Mueser, et. al., 2003).

The Places for People integrated treatment program has made a promising beginning. More rigorous data collection, continued collaboration with other community organizations, and continued emphasis on harm reduction should help the program continue to grow and help more individuals with co-occurring disorders.

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“Damp” housing refers to an apartment building or other housing development in which the use of alcohol or other drugs is tolerated. Illicit drugs are not allowed on the premises, but tenants who use substances are not automatically evicted, as is the case with many housing programs offered by mental health and substance abuse agencies (Mueser et. al., 2003).

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Instrumentalism in occupational therapy: A theoretical core for the Pragmatic Conceptual Model of practice

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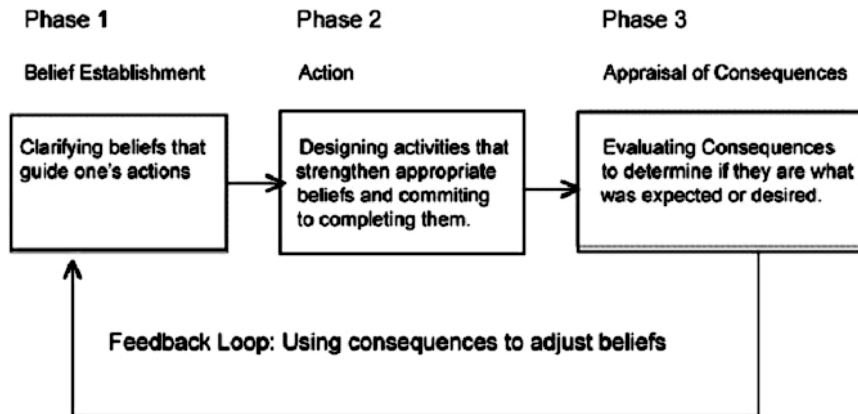
Abstract

In an earlier paper (Ikiugu, 2003), an argument was made for establishment of a pragmatic conceptual model of practice in occupational therapy. It was suggested that in this model, the pragmatic construct of instrumentalism be operationalized as a way for therapists to access the client's mind as a tool for occupational functioning and adaptation to the environment. In this paper, theoretical concepts/constructs used to construct a theoretical core for the model are identified from a review of the history of occupational therapy, selected literature of the philosophy of pragmatism, and the dynamical complex adaptive systems theory. Justification for the above sources of theoretical constructs/concepts was discussed in the previous paper (Ikiugu, 2003). Postulations are developed connecting the concepts/constructs to form a comprehensive, internally consistent theoretical core.

Introduction

In an earlier paper (Ikiugu, 2003) an argument was made for a proposed conceptual model of practice based on the philosophy of pragmatism, which has been proposed as the philosophy that guided the maturing of the idea of occupation as therapy in the early 20th century (Breines, 1986; Hooper & Wood, 2002). It was asserted that practice based on such a philosophy would be consistent with the occupational therapy roots because it would provide interventions that are primarily based on the concept of the mind as a means of activating mind-body action through occupation. In the proposed model, it was suggested that the pragmatic construct of instrumentalism (Dewey, 1957; 1996b; 1996c) be operationalized to inform practice which centers on the notion of the mind as an instrument which can be accessed to facilitate occupational functioning that is geared towards helping the client to be more adaptive in his/her environment for the purpose of both physical and psychological survival. The proposed model consists of three phases as illustrated in figure 1.

**Figure 1. Illustration of Instrumentalism in occupational therapy:
A pragmatic conceptual model of practice.**



Following Mosey's (1996) guidelines on how to establish sets of guidelines for practice, development of the model began with a definition of the problem, which was identified as diminishing identity of occupational therapy as indicated by declining involvement of the profession in mental health practice, and lack of use of occupation-based, client-centered, holistic interventions in practice (Ikiugu, 2003). In this paper, discussion of the theoretical core of the proposed conceptual model will be presented. Concepts/constructs will be identified from the occupational therapy historical literature, the philosophy of pragmatism, and the dynamical complex adaptive systems theory. Postulations will be synthesized connecting the concepts/constructs into a comprehensive, internally consistent theoretical core. Guidelines for problem identification and intervention will be outlined in another paper.

Concepts/constructs used to formulate a theoretical core

Concepts/constructs from the historical literature of occupational Therapy

From the historical literature of the profession are derived constructs of the mind, occupation, individualization, and the environment.

The Mind

The founders of the profession viewed occupational therapy intervention as invariably beginning with the human mind. Pinel (1962, p. 108) suggested that in the moral treatment, "... insanity was curable in many instances, by mildness of treatment and *attention to the state of the mind* exclusively, ..." (italics mine). He thought that impairment of the ability to use the mind to reason diminished a person's humanity, such that, "The figure of the human species is now all that remains to him, 'and like the ruins of a once magnificent edifice, it only serves to remind us of its former dignity and grandeur,' and to awaken our gloomiest reflections-our tenderest regret for the departure of the real and respectable man" (pp. xvi-xvii). He proposed use of occupation to treat individuals who are mentally ill because occupation is the best way to reach the

human being at the most intelligent level. The founders of occupational therapy in the 20th century such as Dunton (1957a; 1957b) and Barton (1980) also aimed at training the mind and body in the appropriate habits of thinking and acting. The individual patient's interests and aspirations were carefully considered (Dunton, 1957b; Licht, 1957). The founders of the profession considered the mind and its functions such as reasoning, thinking, and developing interests to be central to occupational therapy intervention.

Other attributes of the mind that the founders of the profession emphasized included the ability to learn. Barton (1980) stated that the purpose of occupation in the hospitals was to re-educate patients so that they can function effectively in their environments. Similarly, one of the principles advanced by Dunton (1957b) was that a therapeutic activity should in some way increase the patient's knowledge. The ability to pay attention is also a function of the mind that was important for these early occupational therapists. One of the purposes of employment and recreation was to facilitate regaining of the habit of attention (Licht, 1957) and in the process to aid in, "... training emotional control..." (Dunton, 1957b, p. 52). In regaining the habit of attention, patients learnt to discipline themselves and to control and master their disorders (Creek, 2002; Tuke, 1964).

Occupation

Both Pinel (1962) and Tuke (1964) used occupation as an alternative to restraint in the management of the mentally ill patients. According to Pinel (1962), a way to secure health, to keep good order and well-mannered patients, was through interesting and laborious employment. In this regard, he stated that, "The fatigues of the day prepare the labourers for sleep and repose during the night". A link between occupation and health has often been postulated in occupational therapy literature. Wilcock (1998) developed a theory to explain this link. She postulated that humans have evolved as occupational beings because it is through occupation that they adapt and insulate themselves from the environment. Breines (1995) regarded occupations as tools that have enabled humans to survive and to develop over the ages.

Individualization

Individualization refers to the idea of tailoring therapy programs to the specific needs of patients. During the moral treatment era, Pinel (1962, p. 189) instructed that, "... the peculiarities of each case must be watched, studied and treated with such assiduity and address as may promote a speedy and permanent cure." This individualized, client-centered approach was reiterated at the turn of the 20th century by Barton (1980) and Dunton (1957b), who considered the patient's interests as central to the choice of therapeutic occupations for that patient. In current occupational therapy literature, the construct of individualized therapy is prevalent with compelling arguments for therapy to be a collaborative effort between the patient and therapist where the two set goals and plan interventions together (Law, et al., 1998; Rahman, 2000; Schwartzberg, 2002; Thesen, 2000; Wressle, Marcussion, & Henrikson, 2002).

Environment

During the moral treatment movement, both Pinel and Tuke postulated that an environment that was conducive to regaining health for the mentally ill was one that was similar to that of the family (Bing, 1981; Hergenbahn, 1997). Pinel (1962, pp. 206-207) stated that: "In a word, the general government of the hospital, resembled the superintendent of a great family, consisting of turbulent individuals, whose fury it should be more the object to repress than to exasperate, to govern by wisdom rather than to subdue by terror." In other words, the therapist (governor) was to be more or less like a parent, strict, yet gentle and caring. Similarly, Tuke (1964) described the use of moral treatment at the York retreat in England as consisting of kind treatment by the caretakers combined with a comfortable environment consisting of enjoyable social activities and other amusements that the patients enjoyed. It was postulated that patients would be able to recover their use of reason if they were engaged in a regimen of daily activities in the company of other persons of sound mind and a kindly nature (Bockoven, 1971).

At the turn of the 20th century, the founders of occupational therapy continued to emphasize the role of the

environment, both physical and social, in occupational therapy. Barton (1980) saw occupational therapy as a means of solving economic problems whereby dependents were reclaimed to be independent producers, and thus to contribute economically in their environment. In developing his principles of occupational therapy, Dunton (1957b) stipulated that the best occupations were those that were "...interesting" (p.47) to the patient and should, "... lead to an increase in the patient's knowledge" (p. 47). The emphasis on increasing the patient's knowledge indicates the importance of engagement of the patient with the environment since knowledge comes from synthesis of environmental experiences (Locke, 1924). Later, Meyer (1977) held that mental illness was a result of maladaptive interaction between the person and his or her environment. He proposed that the problem of mental illness is a problem of adaptation. Occupation was, according to him, a means by which a person maintained balance in his/her environment and therefore remained healthy. The theme of a healthy person as one who interacts effectively with and adapts to the environment has continued in the professional literature to the current time (Law, et al., 1998). The context within which the patient lives (community) is increasingly appearing in literature as a major focus of the profession (Gaudet, 2002; Townsend, 1998).

Concepts/constructs from the philosophy of Pragmatism

Some of the concepts/constructs from the philosophy of pragmatism that are used in the proposed conceptual model include beliefs, activity, contextualization, experience, consequences, and instrumentalism.

Beliefs

According to Peirce (1955b, p. 7) reasoning helps us to, "... find out, from the consideration of what we already know, something else which we do not know." Good reasoning should lead us to draw true conclusions from true premises (Fisch, 1996). The ability to reason well is dependent on factually grounded premises and ensuing conclusions. The premises from which conclusions are drawn are the beliefs that one holds. When an action based on a belief does not lead to expected consequences according to experiential facts, doubt results. Doubt causes irritation and belief causes a calming of the mind. Belief is therefore the state towards which the mind tends (Herzoghahn, 1997). When a belief is established because actions based on it result in expected or desired consequences, a habit is established because the same action will recur in future.

James (1996, p. 136) defined a belief thus: "LET US GIVE the name of *hypothesis* to anything that may be proposed to our belief; ..." He considered a belief to be a theory about how things are. Its potency is determined by the willingness to act on it. If a belief or hypothesis is valid, then a person is willing to act on it. He reiterated Peirce's (1955b) position that the test of a belief is the practical consequences of action arising from that belief (James, 1996; 1977b; Mounce, 1997). He saw the truth of a belief as being determined by the extent to which the consequences of actions based on it are expected or desirable. In the pragmatic conceptual model of practice for occupational therapy, the challenge will be to determine what beliefs motivate a client's actions and to help the client examine the consequences of actions arising from those beliefs to determine if such consequences were expected or desirable.

Activity

Since according to both Peirce and James a belief is a rule for action (James, 1977a; 1977b; Mounce, 1997; Peirce, 1996a), it follows that a belief without action/activity is meaningless for there are no consequences of holding such a belief. Without consequences, the belief cannot be evaluated. This pragmatic valuing of activity is consistent with the view in occupational therapy, that a healthy individual is one who is active (Barton, 1980; Bing, 1981; Creek, 2002).

Consequences

As a rule of action, application of a belief involves doubt and therefore a thought process whose aim is to establish belief and appease the irritation of doubt (Peirce, 1955b). Belief is therefore the beginning and end

of thought. Since thought is the means by which belief is established, its soundness can also be judged only according to action(s) resulting from it. According to Peirce (1955b, p. 10) the practical consequences of action resulting from a belief or an idea constitute the only sensible meaning of that belief or idea since, "It is certainly best for us that our beliefs should be such as may truly guide our actions so as to satisfy our desires; and this reflection will make us reject every belief which does not seem to have been so formed as to insure this result." In occupational therapy, consequences are similarly valued since the goal of therapy is to effect change in positive ways (Bruce & Borg, 1993; Creek, 2002).

Experience

The pragmatists' philosophy was highly influenced by the British empirical philosophical ideas, especially those of John Locke (Buchler, 1955; Fisch, 1996; Hergenhahn, 1997; Whittemore, 1964). Locke's (1924; 1990) basic premise was that all knowledge arises from experience. In this regard, he said:

2. *All ideas come from sensation or reflection.*—Let us then suppose the mind to be, as we say, white paper, void of all characters, without any ideas; How comes it be furnished? To this I answer, in one word, from EXPERIENCE. In that all our knowledge is founded, and from that it ultimately derives itself. ... (Locke, 1924, p. 42)

Similarly, Peirce (1955b) stated that experience is not only the source of knowledge but also the compass with which humans must navigate life. James (1977b, p. 136), extended this idea in his doctrine of radical empiricism where he asserted that, "... the only things that shall be debatable among philosophers shall be things definable in terms drawn from experience." Dewey (1957) argued for reconstruction of philosophy on the premise that a philosopher, like a scientist, should adopt the experimental method of pursuing knowledge rather than introspective rationalization. In adopting the experimental method, the philosopher would draw from experience as the source of knowledge. The importance attributed to experience by pragmatists is consistent with the value of environment in occupational therapy (Creek, 2002; Law, et al., 1998), since environment is the source of experience.

Instrumentalism

Instrumentalism refers to the principle drawn from Darwin's (1859) theory of evolution which postulates that humans are not apart from nature but are part of it (Dewey, 1957; Sibley, n.d.). Dewey derived this notion from William James (1996, see also Whittemore, 1964). James (1977c, p. 11) argued that the mind, "... seems endowed with a very extraordinary degree of plasticity ...; so that we may without hesitation lay down as our first proposition the following: that *the phenomena of habit in living beings are due to the plasticity of the organic material of which their bodies are composed.*" Arguing further about the importance of habit in regulation of human function, James (1977c) suggested that the brain evolves from interaction between the human being and the environment, since this interaction is what provides the experiences that result in habit formation. Through this interaction, the environmental experiences shape the neural system (James, 1977c). He anticipated human agency that is central to instrumentalism by arguing that the human being (knower) is an actor rather than a passive observer of nature. As an actor, he or she uses mental interests, hypotheses, and postulates, as the basis of action. These faculties of the mind function to transform the world and in so doing, help make true what they declare (James, 1920). Dewey (1931) found in this postulation by James a method of using philosophy to make the world better. He argued that intelligence is basically an instrument to effect individual and social progress (Whittemore, 1964).

According to Dewey (1929), intelligence should be viewed as a tool or an instrument in the same way that other tools or instruments are made and used with precision to solve the environmental and social problems. Intelligence is employed this way through formulation of appropriate theories to inform action that would improve the situation in the world. Any theory then, which is divorced from doing, is useless and futile. The construct of instrumentalism therefore touches on many themes embraced by occupational therapists, such as

doing, agency, and the environment (see Creek, 2002; Dunn, Brown, & McGuigan, 1994; Schwartzberg, 2002).

Contextualization

The whole of Dewey's philosophical orientation may be summed up with the construct of meliorism (Fisch, 1996; Whittmore, 1964). His goal was meliorism in the sense that he sought a method of doing philosophy to serve democracy and solve contemporary social problems and thus make the world a better place to live. Such a philosophy had to be placed in the social context (contextualization). Occupational therapists are familiar with this notion considering that they are primarily interested in how humans can make their lives better by interacting and functioning occupationally within the environmental context (Bruce & Borg, 1993; Creek, 2002; Dunn, et al., 1994; Law, et al., 1998; Schwartzberg, 2002).

Concepts/constructs from the dynamical systems/complexity theory

According to this theory, living systems are complex adaptive dynamical systems (Anonymous, 2001; Waldrop, 1992). Life emerges at the point where matter is beginning to be chaotic but still has some order to give it structure (Waldrop, 1992). In other words, the boundaries of life (indicated by creative productivity), are order and stagnation on one end and chaos on the other (Arndt & Bigelow, 2000). This delicate balance is what produces creativity, which is one major characteristic of complex adaptive evolving systems.

Humans can be conceptualized as complex adaptive evolving systems. It is postulated in this paper that the extent to which they maintain balance between chaos and order in their thinking and activities defines the extent to which humans are alive. This view is similar to the principle of occupational adaptation advanced in the *Occupational Adaptation Frame of Reference* (Falk-Kessler, Julin, Padilla, & Schultz, 1998; Schkade & Schultz, 1992; Schultz & Schkade, 1992). In this frame of reference, an adaptive individual is conceptualized as one who blends mobility and stability through occupational performance to produce mature behavior. In the proposed pragmatic conceptual model of practice, concepts/constructs derived from the dynamical systems/complexity theory will be: 1) Disproportion between initial conditions and final outcomes; 2) Emergence; 3) Fractal nature of human occupational behavior; 4) Strange attractors.

Disproportion between initial conditions and final outcomes

Complex dynamical systems exhibit a phenomenon known as non-linearity (Cambel, 1993). This means that the behavior of such systems cannot be understood in simple linear mathematical equations. There is no simple cause-effect coupling. Such systems are open (i.e., they exchange information with their surroundings), are neither completely deterministic nor completely random, and paradoxes exist within them (Cambel, 1993). There is uncertainty within such systems making precise prediction of outcome difficult. This property of dynamical systems explains one of their major characteristics, namely, that small differences in initial conditions can cause extensive differences in consequences (Arndt & Bigelow, 2000; Bolland & Atherton, 1999; Cambel, 1993; Whiting, 2001).

This theory may be used to explain the interaction between occupational performance and health. Engagement in occupation results in varied and unpredictable health outcomes, both physical and psychological, which may not be easily explained by cause-effect coupling (Kielhofner, 1997). Occupation organizes behavior generally and does not affect only the musculoskeletal, neurological, and mental components towards which it may be directed. The other use of this concept may be to enable therapists to explain to patients the importance of their actions. A person's beliefs and subsequent momentary decisions and actions may have significant effects not only on the person's life but also on other people and the environment. For instance, deciding to stay in bed instead of attending an important business meeting may lead to a loss of job and income, affecting the childrens' education, family well-being, and the entire community's economy in unpredictable ways. It should therefore be emphasized to clients that they should not only strive to be agents in their environment in order to satisfy their needs, but as co-agents, they also have a responsibility to their

families, entire communities, and the environment in which they live (Arndt & Bigelow, 2000).

Emergence

One characteristic that distinguishes dynamical complex adaptive systems from other systems is that they are self-organizing (Mendenhall, Macomber, & Curtright, 2000). This means that parts in the system cooperate to produce structures performing totally different functions than those performed by the parts (Cambel, 1993). This self-organization is what makes evolution possible. In the process of responding to the environment in order to reach its goals (Anonymous, 2001), the primary one of which is to survive, the organism creates new structures. Cells organize themselves functionally into tissues that are specialized according to function, tissues organize themselves into organs, organs into systems and systems into a functional organism. At each level of organization, properties specific to that level and that transcend the sum of individual parts emerge (Bell, Baldwin, & Schwartz, 2002).

The property of self-organization and emergence has significant implications for how occupational functioning of human beings may be viewed. First, the symptoms that a client presents may be seen as emergent indicators of a dysfunctional or maladaptive life. This is the view adopted by homeopathic practitioners (Bell, Baldwin, & Schwartz, 2002) and it seems to be a view that may describe the kinds of problems encountered in occupational therapy. This may explain why two individuals with the same condition, same age, and the same physical characteristics react differently to the condition (Bruce & Borg, 2002). One person may disregard the discomfort posed by the condition, apply her/himself, and make progress and recovery. The other person may react with despair, see him/herself as helpless, refuse to do anything, and gradually deteriorate mentally and/or physically even to the point of death. The differences between the characteristics of the two individuals may be emergent indicators of the underlying individual beliefs about themselves. As therapists, one way to intervene in an attempt to help such individuals, may be to help them clarify their underlying beliefs and the resulting occupational behaviors that produce the consequences that they experience in their lives. It is hypothesized that by clarifying self-defeating beliefs that hinder achievement of occupational goals, they can substitute such beliefs with ones supportive of more appropriate occupational functioning, leading to desired consequences.

The other application of emergence may be in the way occupation is conceptualized to work in clients' lives. In the complex adaptive dynamical systems theory perspective, it could be postulated that through occupation, therapists apply small inputs at the point when they come into contact with patients. Such inputs may, for example, be inculcating habits that are consistent with their goals. For instance, a teenager who wants to excel in academics may choose to read over engagement in another activity until reading becomes a habitual activity. An elderly person who wants to be independent may be asked to make small independent decisions such as what to wear, and what activities to engage in within a rehabilitation unit on a regular basis. The hypothesis behind this approach would be that such behaviors would eventually lead to emergence of positive characteristics, which may generalize into the patient's entire life, leading to achievement of desired occupational goals such as being an academically astute person, or an independent person. While the author is aware that there is no empirical evidence to support such a hypothesis, it can be tested in practice using type II applied scientific inquiry (Mosey, 1996) once the model begins to be applied in practice.

The fractal nature of human occupational behavior

Fractality in complex dynamical systems refers to self-similarity at every level of self-organization (Bell, Baldwin, & Schwartz, 2002) such that at every scale, parts are smaller, exact duplications of the whole (Bassingthwaighte, Liebovitch, & West, 1994). This self-similarity may be either geometrical or statistical. Geometrical self-similarity is found in nature in symmetrical structures, such as the division of blood vessels in the human body (Bassingthwaighte, Liebovitch, & West, 1994). The truncation of vessels is symmetrical, so that any capillary system has the same number and system of truncation as that at the level of the veins, or

arterioles. In statistical self-similarity, parts are "... 'kind of like' the whole." (P. 13), which means that statistical properties of the parts are proportional to those of the whole.

Statistical self-similarity may be useful in evaluation and study of human occupation in an attempt to understand why an individual client is adaptive or maladaptive in different life circumstances. The assumption would be that the general adaptability or maladaptability is manifested in the pattern of individual moment-to-moment choices. For instance, consider a teenager who wonders why he is not succeeding in school. You analyze the teenager's occupational behavior in the occupational therapy clinic and discover that every time you give him a challenging task, he engages in it for a few minutes, then loses interest and starts playing video games. You realize that this is a pattern in his life. Whenever he is faced with a challenge, he has a tendency to escape into games. In this model, it is hypothesized that his behavior while engaging in occupation in the occupational therapy department is a fractal. This means that each part of the client's activity lifestyle is similar to the whole pattern of performance in his life.

Strange attractors

The field within which dynamical complex adaptive systems move is known as the phase space (Cambel, 1993). Movement by the system within this space constitutes what is known as a trajectory (Bassingthwaighte, Liebovich, & West, 1994). A trajectory could, for example, be a person's occupational life in terms of the various activities engaged in over a life-time. When simple systems such as oscillators are displaced from a starting point, they eventually come to rest at that point (Bassingthwaighte, Liebovich, & West, 1994). For example, a displaced pendulum moves within the phase space until it comes to rest at the starting point, which is a point of stable equilibrium. Such fixed points within which the system eventually comes to rest are predictable and are known as fixed attractors (Bassingthwaighte, Liebovich, & West, 1994; Cambel, 1993).

In dynamical systems, the region within which the attractor is situated is called a basin of attraction (Cambel, 1993). The set of initial conditions form the basin of attraction (Alligood, Sauer, & Yorke, 1996). In occupational therapy, such conditions could be self-esteem, beliefs, values, interests, and so forth. Fixed attractors are predictable and irrespective of initial conditions, the system eventually comes to rest at them. In dynamical complex adaptive systems, attractors are not fixed. Furthermore, two or more points within each attractor may determine the trajectory for each of the initial conditions. Such attractors are sensitive to initial conditions, so that initial differences lead to magnification of the differences between points within the attractor. In other words, the points within the attractor diverge from each other (Bassingthwaighte, Liebovich, & West, 1994). However, the divergence is finite. Consequently, the trajectories from the nearby initial points on the attractor diverge, and then are folded back onto the attractor repeatedly. This creates layers of the trajectory, which are self-same, and therefore, the attractor becomes a fractal. In such fractal systems there is energy expenditure and they rely on exchange of energy and information with the environment for survival (Bassingthwaighte, Liebovich, & West, 1994). Attractors in such systems are unpredictable and are known as strange or chaotic attractors (Abraham, McKenna, & Sheldrake, 1992; Alligood, Sauer, & Yorke, 1996; Bassingthwaighte, Liebovich, & West, 1994; Cambel, 1993).

Kielhofner (1997) explains the phenomenon of the attractor as a tendency for the system to behave in a certain way. In the pragmatic conceptual model, it is proposed that the attractor for human occupational functioning is the purpose of occupation. This attractor may have more than one point of attraction such as the need for a person to feel competent in his or her environment as well as the need to earn a living and survive. Depending on the initial conditions, the two points may diverge exponentially. For example, if one has poor self-esteem, pursuing tasks may be mostly to earn wages for survival purposes. The need to do things to enhance feelings of competence becomes secondary. The two points then become polarized. If, however, the initial condition is good self-esteem and therefore a feeling that one can achieve whatever he or she puts his or her mind into, then competence and earning a living are perceived as equally achievable goals. The two goals are pursued in

tandem and there is no great divergence between the two points in the attractor (purpose of engagement in occupation).

A concise statement of the theoretical core of the pragmatic conceptual model of Practice

Based on the complex dynamical adaptive systems theory, the human being may be conceptualized as a complex adaptive dynamical system who is engaged in interaction with the environment, both physical and social, through occupational performance, for the purpose of changing, adapting, creating, and therefore surviving. According to the philosophy of pragmatism, this adaptive system employs the mind as an instrument to shape the environment so that it is suitable for human survival (Dewey, 1957; 1996a; 1996b; Muelder, Sears, & Schlabach, 1990; Sibley, n.d.; Whittmore, 1964).

Engagement of the mind as an instrument for adaptation to the environment involves formation of beliefs as a basis for thought, which directs actions (James, 1977a; 1977b; 1981; 1996; Peirce, 1955a; 1955b). Use of the mind also involves awareness of the consequences of actions that include knowledge of the gravity of initial conditions. It is postulated that agency in one's environment is best achieved if there is awareness that small differences in initial conditions at any point may lead to extensive differences in outcomes. This is true not only in an individual's life but also in the lives of those close to him or her, and the entire community (context). As such, the moment-to-moment decisions that one makes as guided by beliefs, and the resulting occupational activities make a significant difference in the world.

Adaptability or maladaptability depends on how well a person functions in daily occupations. An adaptive person continually emerges, so to speak, through action, a phenomenon that may be called self-determination. A maladaptive person is either too rigid or too disorganized, and is unable to accomplish many things in life. If too rigid, the person may not be able to conceptualize alternative ways of doing things when known strategies do not work (Schkade & Schultz, 1992; Schultz & Schkade, 1992). If too disorganized, the person is unable to focus and keeps flitting from one task to another without any accomplishments, as seen in a person suffering from hypomania. Whether a person is too rigid or too disorganized, the result is stagnation and inability to have an experience of satisfaction with life. Human occupation may be conceptualized as a fractal (Bassingthwaite, Liebovich, & West, 1994). A therapist is able to assess whether a patient is stagnated (maladaptive) or adaptive by examining a part of the patient's occupational life trajectory in the clinic. As a fractal it is assumed that occupational life trajectory has self-same properties. Therefore, by examining a part of the trajectory, the therapist is able to judge whether the client exhibits a pattern of adaptability or maladaptability.

Once it is determined that a client is maladaptive, the goal of intervention is to facilitate emergence of adaptive patterns. This would be accomplished by accessing the client's mind as a tool to effect functional change. To do this, the therapist would determine what beliefs form the basis of occupational actions for the patient and whether such beliefs support an adaptive or maladaptive lifestyle. For example, consider a young man who believes that he is not intelligent enough to accomplish tasks requiring intellectual acumen such as is required for the bookkeeping that is necessary for him to be able to run his own business. He has some good ideas that may lead to establishment of a successful business, but as long as he believes that he is incapable, he will not be able to act in a manner to actualize his ideas.

In such a case, the therapist may want to educate the client regarding how his beliefs may be inconsistent with an adaptive lifestyle, in this case being able to achieve his dream of establishing his own business. The goal would be to help the young man to substitute such beliefs with ones that support an adaptive lifestyle leading to taking concrete steps towards achieving his dream of starting a business. Once it is determined what negative beliefs the client needs to substitute in order to be adaptive, he or she would be asked to make occupational decisions on the basis of newly formulated positive beliefs and act on them in the clinic. In the

hypothetical case of the young man mentioned above, the therapist may want to help him substitute the belief that he is not intelligent enough with one that he is capable of bookkeeping or any similar task that requires some mathematical aptitude. This may be accomplished in the clinic by asking him to be a bookkeeper for a project group in the occupational therapy department. The therapist can then point out how successful the client is in the task and thus challenge his belief about lack of aptitude, or encourage him to accurately assess his strengths and, if necessary to the success of his business, hire a bookkeeper.

The rationale for the above-described intervention is that beliefs form a basin of attraction for the client. The purpose of engagement in occupation is a strange attractor (see discussion on ‘the basin of attraction’ and ‘strange attractors’ in Alligood, Sauer, & Yorke, 1996; Bassingthwaite, Liebovich, & West, 1994; Cambel, 1993). For the client to be conscious of this attractor, the purpose of occupational activity must be stated clearly in the form of goals. In the case of the young man, the purpose of putting him in charge of bookkeeping for the project group would be to demonstrate to him that he is capable of successfully completing tasks that require mathematical aptitude or to recognize that he is unable to successfully complete such tasks and therefore needs to pursue other options. Once beliefs are clarified and a purpose in form of goals is stated, the therapist gets a commitment from the client that he or she will act on the newly established beliefs at every instance outside the clinic. For example, the young man may be asked to commit to engaging in leisure activities, such as playing chess, which require abstraction, planning, forward thinking (anticipation), pattern recognition, and connecting moves with consequences, which are the same skills required in mathematically oriented tasks, at least once a week in between therapy sessions.

The therapist and client monitor consequences of the client’s actions and decide whether they are what is expected or desired. If they are what were expected or desired, the client has been transformed from a maladaptive to a dynamical adaptive system and therapy is terminated. If the consequences of the client’s actions both in and outside the clinic are not what was expected or desired, the therapist in collaboration with the client re-examines the beliefs upon which the client is acting and adjusts them and therefore the activities they guide accordingly. The expected result of intervention is adaptability, conceptualized as emergent behavior, which enables the complex dynamical human system to use the experience available from the environment to change and recreate itself, and therefore to adapt to the context and to survive both physically and psychologically.

Conclusion

The purpose of this paper was to present a theoretical core for a proposed pragmatic conceptual model of practice in occupational therapy which focuses on the mind as an instrument for human adaptation to the environment through occupational functioning. The theoretical core, consisting of constructs/concepts derived from the professional historical literature, the philosophy of pragmatism, and the dynamical systems/complexity theory, was discussed. The specific guidelines for practice based on the proposed conceptual model of practice and recommendations for type II applied scientific inquiry to assess adequacy of the guidelines (Mosey, 1996) will be presented in another paper.

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Instrumentalism in Occupational Therapy: Guidelines for Practice

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Abstract

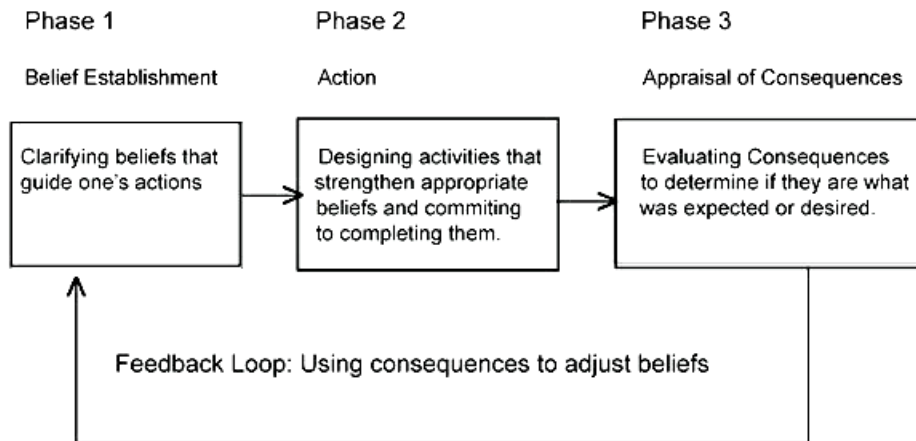
This paper discusses the guidelines for application of the pragmatic construct of instrumentalism (Dewey, 1957; Sibley, n.d.) in the practice of occupational therapy. The guidelines are based on a theoretical core of the conceptual model developed earlier by the author (Ikiugu, 2003a; 2003b). The model is based on the postulation that the mind is an instrument for human adaptation to the environment. Use of this instrument is dependent on the beliefs about self, others, and the world. In this paper, guidelines for clarification, establishment, and reinforcement of beliefs that support performance of activities that lead to desirable consequences and therefore a purposeful and meaningful life are presented.

Introduction

Ikiugu (2004a; 2004b) suggested that practice that demonstrates uniqueness of occupational therapy might be developed by focussing practice on the mind as an instrument for human occupational functioning. He argued that this was the basic premise of the founders of occupational therapy. In proposing a model of practice that emphasizes the instrumental role of the mind, he drew theoretical concepts from the occupational therapy historical literature, the literature of American pragmatism, and

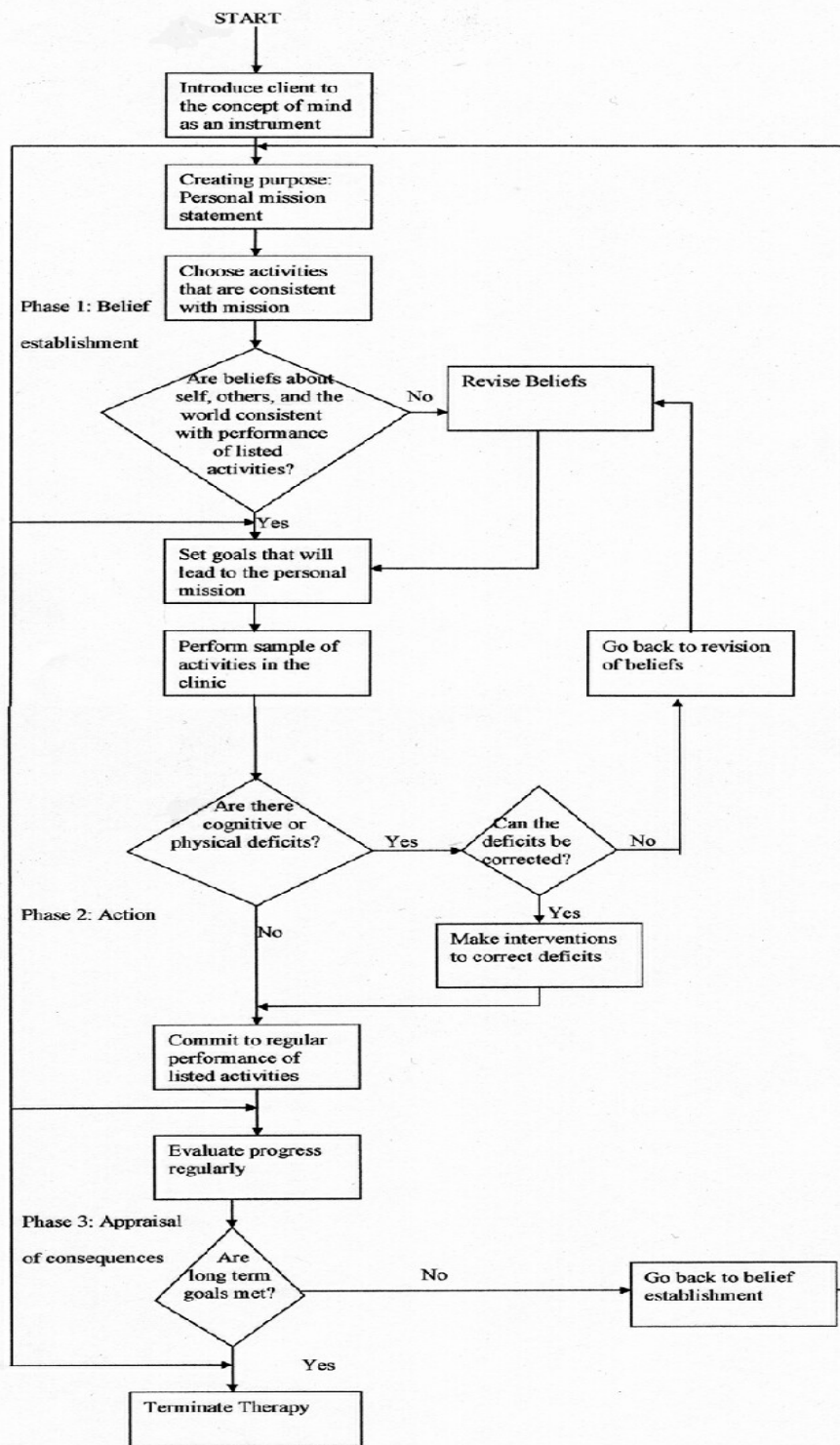
the complexity/dynamical systems theory. He proposed a model of practice based on the theoretical core from the above sources that consisted of three phases, namely, the belief establishment, action, and consequence appraisal phases (see figure 1).

Figure 1. Illustration of Instrumentalism in occupational therapy:
A pragmatic conceptual model of practice.



The purpose of this paper is to extend the proposed model of practice by outlining specific guidelines for problem identification and intervention at each of the three phases. The therapeutic process using the model illustrated in the flow chart on figure 2.

Figure 2. Instrumentalism in occupational therapy:
 Therapeutic process illustrated.



The therapeutic guidelines for application of the conceptual model in clinical practice following the steps outlined in figure 2 and their rationale are discussed below.

Phase 1: Belief Establishment

It is hypothesized in this model that when clients seek occupational therapy services, it is because they have lost what Assagioli (1973, p. 44) calls "... harmony in our being, and harmony in a universal law of life." This view is consistent with Meyer's (1977) contention that mental illness results from a loss of balance between work, leisure, rest, and sleep which must be maintained even under extreme difficult if the human being is to remain healthy. This loss of balance/harmony is a result of disruption of the "... ordered rhythm of daily activities" (Assagioli, 1973, p. 44).

Ikiugu (2004a; 2004b) proposed that in occupational therapy the client can be conceptualized as a complex dynamical adaptive system. Such a system is engaged with its environment for the purpose of creating, changing, adapting and surviving (Allgood, Sauer, & Yorke, 1996; Anonymous, 2001; Basingthwaite, Liebovich, & West, 1994; Waldrop, 1992). It is the quality of engagement with the environment which makes it possible for such a system to evolve and to be alive. When the system loses the ability to engage the environment and evolve, it becomes maladaptive rather than adaptive, and to that extent, it is not fully alive. It is proposed in this paper that loss of rhythm in daily activities and the resulting disharmony leads to the human being, as a live, complex, dynamical adaptive system, being maladaptive. Such a system is not able to fashion out the environment, whether physical or social, to make it suitable for physical and psychological survival (Dewey, 1990).

Maladaptivity may be due to stagnation resulting from rigid or chaotic behavior, which may originate from physical or psychosocial difficulties (Schkade & Schultz, 1992; Schultz & Schkade, 1992). In this paper, it is proposed that such stagnation starts primarily with the mind in the form of maladaptive beliefs and thought patterns which are used as the basis for action (Bruce & Borg, 2002; James, 1996; James, 1977a; Mounce, 1997; Peirce, 1955; Stein & Cutler, 2002). It is therefore proposed that therapy begin with clarification of beliefs and thought patterns on which the client's actions are based. The client should be led to attain insight regarding how such beliefs and thought patterns lead to maladaptive activity.

Phase 1: Belief Establishment

Guidelines for belief and thought pattern clarification

1. Introduction

The client is first introduced to therapy by explaining the concept of the mind as an instrument for adaptation. It is explained that the mind is a tool, just like any other, that the client can use for occupational performance in order to achieve desired goals. Any tool is useful only if used correctly. It is explained to the client that the purpose of therapy is to explore how to use the mind to live adaptively in the environment. To accomplish this goal, the client is shown that a commitment to honest self-exploration and to changing in accordance with self-discovery is necessary.

2. Creating a purpose: Personal mission statement as a systemic attractor

The second step in the belief establishment phase is to assist the client to clarify his/her perceived purpose in life. Purposefulness here refers not only to goal-directed activities, as have been defined in occupational therapy literature (Bruce & Borg, 2002), but also to a person's life in general. A person is living a purposeful life when he or she has a sense of mission or reason for existence (Covey, 1990; McGraw, 2001). Purposefulness is closely related to meaningfulness. Frankl (1984) stated that the task of human beings is primarily to find meaning in life. He postulated that there are three ways in which people try to discover this meaning. These are, creating work or doing, experiencing a sense of goodness in life and in other people, and taking a positive attitude towards unavoidable suffering. Frankl thus identified creativity in work (occupation), the same condition for purposefulness (Csikszentmihalyi, 1996), as one way that people create meaningful existence.

Purpose or sense of mission is an attractor for the human complex dynamical adaptive system (Ikiugu, 2004b). McGraw (2001) illustrates this view particularly well when he compares purpose to gravitational force. He explains that when people work against their purpose in life, it is like working against gravity. He states:

... You have certain core traits, qualities, gifts, talents, needs, and desires. You have a core purpose for being in this world. By suppressing who you were meant and need to be, you are doing something entirely unnatural. If you are living for the fictional self, then you are unnecessarily trying to hold a beach ball under water with one hand while trying to push a boulder uphill with the other... (pp. 32-33).

By holding a beach-ball under water and pushing a boulder uphill, McGraw (2001) means that you are defying what is natural, as one would defy gravity by pushing a boulder uphill or the floatation energy of a beachball by trying to hold it under water. Gravity, floatation energy, and purposefulness are all natural attractors for systems as explained in dynamical systems theory (Bassingthwaighte, Liebovich, & West, 1994; Campbel, 1993). This view is reiterated by Briggs and Peat (1989), who consider purpose or final goal as a future reference point that pulls the system's movement in a similar way as an attractor in chaos theory. That is why clients need to start by clarifying a sense of mission that informs the purpose of their lives.

When individuals do things that are in accordance with their purpose, they are inspired (Dyer, 1998; McGraw, 2001). This means that they do what they really enjoy doing. Such activity is accomplished effortlessly, almost as if it is play (McGraw, 2001). A person living such a life is excited and looks forward to engaging in tasks and activities. Research has shown that a purposeful life consists of: 1) Subjective well-being (consisting of happiness and satisfaction with life); 2) Personal growth (consisting of self-actualization and a sense of meaningfulness); and 3) Other-centered religiosity (or a focus on helping other people, a phenomenon known as altruism) (Compton, 2001; Rhoades & McFarland, 2000). It is suggested in this paper that the therapist lead the client in establishing a personal mission statement, which clarifies the person's sense of purpose. To accomplish this, the guidelines by Covey (1990) may be helpful.

Covey (1990) states that what we want must be created in the mind before it is physically realized. Creating a personal mission statement is necessary to clarify the purpose in the mind leading to actualization through activity. To do this, he recommends that you imagine that you are dead and your eulogy is being read. Write down what you would like each of the following to say about you in the eulogy: a) Family member, such as spouse, parent, sibling, cousin, and so on. b) Friend. c) Work/professional associate. d) Representative of a Church/community organization with which you are affiliated. Based on what you have imagined each of the above to say about you, write a mission statement. Your statement may begin as follows; "I am committed to accomplishing the following in my life:" The mission statement should include all areas of the client's life: the family, social relationships (friends), work/profession, and affiliation to a church or community organization.

3. Choosing activities that are consistent with the personal mission statement

Several suggestions exist in literature regarding how to discover what activities are consistent with one's purpose in life and to act on them accordingly. Dyer (1998, p. 20) suggests answering honestly questions such as: "When do I feel most fulfilled? When do I feel extraordinary or like a great person?" He suggests that answers to such questions often are associated with doing something for a cause greater than just personal pleasure. Such a cause could be other people, or the planet. McGraw (2001, p. 29) suggests questions such as: "Why are you doing what it is that you do? Is what you are doing with your life something that reflects and utilizes who you really are? Given a choice, would you choose differently? Do you even know what you would choose if you had an option? ..." He suggests that answers to such questions would enlighten you regarding whether you are acting in accordance with your authentic self, which according to him gives life purpose and meaning. Cellini (2000, p. 3) used the following questions as a guide to self-exploration: "Why am I not fulfilled? Who do I want to be? What do I want to do? What level of satisfaction am I seeking?" Answers to all the above suggested questions help the therapist to individualize activities by focussing on

what constitutes the client's personality, desires, needs, and aspirations, or his or her core, or what McGraw (2001) calls the authentic self.

In occupational therapy, the Canadian Occupational Performance Measure (Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 1998) individualizes therapeutic activities in a more structured manner. Using the instrument, the therapist asks a client to identify activities in self-care, productivity, and leisure that he or she wants, needs, or is expected to perform. The client is asked to rate, on a scale of one (1) to ten (10) the importance of being able to perform each activity, (1) being least important and (10) being extremely important. Next, the client is asked to rate him/herself regarding the ability to perform activities rated as important. Each activity is then rated on the same scale regarding satisfaction with performance. Eventually, a maximum of five activities are chosen which are the basis of goal-setting for the client for the following two weeks. The ratings are used to compute an index for performance and another one for satisfaction. After two weeks, the client is re-evaluated, and performance and satisfaction with performance indexes are then calculated again. The difference between the initial and the re-evaluation scores indicate whether or not there is progress as a result of therapeutic interventions.

The Canadian Occupational Performance Measure (Law, et al., 1998) is a good instrument for choosing activities to perform in therapy using a client-centered approach. However, the focus of the instrument is not the purposefulness and meaningfulness of life in general. This paper presents an instrument that extends Law et al.'s (1998) client-centeredness while taking into account the mission statement which provides purpose (attractor) for the client's life (see the Assessment and Intervention Instrument for Instrumentalism in Occupational Therapy (AIIOT) on the appendix). The client is asked to list activities needed in order to achieve the stated mission. In the initial development of AIIOT, it was suggested that for each area of the client's life mission: family, socialization (friends), work/profession, and church/engagement in a community organization, five such activities be chosen based on priority. The idea of five activities or tasks was derived from Law, et al. (1998). On the basis of the activities, five short-term goals were to be formulated for each area of the life mission. When a pilot test of the model was run with a group of students in the occupational therapy department at the University of Scranton (n=12), it became apparent that 20 short-term goals (five for each area of the mission) were too overwhelming. The instrument was therefore revised so that there are 2 short-term goals for each area (8 short-term goals overall).

For each of the listed activities, the frequency with which the client performs it, the adequacy of performance, satisfaction with performance, and beliefs about the ability to perform the activity with acceptable frequency and adequacy are rated on a four-point Likert-type scale (see the AIIOT on the appendix). Ratings are added to obtain summed scores for frequency, adequacy, satisfaction, and beliefs respectively. A less than perfect satisfaction score indicates that a person's sense of meaning and purpose in life may require to be addressed.

4. Clarifying beliefs that guide performance of chosen activities

The basic rationale in this model is that the mind guides performance. This happens because the beliefs that one holds regarding self, others, and the world are the rules of action (Peirce, 1955). In cognitive psychology, such beliefs are conceptualized to be embedded in schemata which are stable knowledge bases consisting of structures representing beliefs, theories, and assumptions, about the self, the world and other people (Gardner, 2002). Without identifying such schemata and how they affect the way clients view their ability to perform activities and the consequences of such performance, it may be difficult to assist them to change their lives in such a way that what they do is consistent with what gives their life meaning and purpose.

It is important to clarify what beliefs guide the person's performance of each activity and how such beliefs may or may not be hindering performance to full satisfaction. The client is then asked to identify the origin of such beliefs. McGraw (2001) argues that there are key defining moments in our lives, which can easily be identified as sources of beliefs that constitute our self-concept. Such moments consist of events and responses

to those events that change a person's outlook to the world for the rest of his or her life. A person has a certain view of self, other people, and the world before the event and a totally different view after the event. For example, one may be trusting and optimistic before perceived betrayal by a significant person, and distrustful and pessimistic after the event. Such events tend to stand out in a person's memory for the rest of his/her life.

According to Adlerian therapists Marcus and Rosenberg (1998), defining moments affect a person either positively or negatively. If the effect is positive, they contribute to a feeling of superiority in the sense that one feels energized to progress towards personal perfection. If the effect is negative, one feels inferior and incompetent to attain perfection. Marcus and Rosenberg (1998) assess such defining moments by asking the client to narrate in detail his or her earliest childhood recollections or dreams. The effects of such events on one's lifestyle are then discussed.

McGraw (2001) has the client identify 10 such defining moments covering the entire lifespan of the person. In this paper, it is argued that identification of 10 defining moments may not be necessary since a person's occupational lifestyle is postulated to be a fractal (Ikiugu, 2004b), which means that it has self-similar properties (Bell, Baldwin, & Schwartz, 2002). This means that identification of only one or a few such moments may help the therapist determine the client's typical response to occupational tasks that are necessary for a purposeful and meaningful life. This fractal view of occupational life trajectory is consistent with Marcus and Rosenberg's (1998) view that the same theme, which can be traced back to the earliest childhood memories or dreams, recurs throughout a person's life.

In the conceptual model discussed in this paper, the client is asked to rate the extent to which he or she believes that he or she is able to perform with acceptable frequency and adequacy each of the activities identified as necessary in order to accomplish the stated life mission. For each activity that the client believes that she or he is not capable of performing with acceptable frequency and adequacy, she or he is asked to remember when that belief was first acquired. For example, let's say that a client's mission is to earn a higher degree and become a counselor so that she can help people solve their problems. For that purpose to be accomplished, the client realizes that she needs to fulfill the admission requirements for the relevant degree. One of those requirements may be getting a certain score on the GRE (Graduate Record Examination). Suppose the client says that she does not believe that she can attain the required GRE score because she is poor in mathematics. Questions that the therapist might ask may include, "when did you first acquire the belief that you are poor in mathematics?" The client may recollect that it was in the third grade when a teacher told her how stupid she was and how she can never achieve anything requiring intelligence such as is required in mathematics.

5. Challenging beliefs that do not support the client's mission

Once beliefs that do not support performance of activities that would enable achievement of the personal mission are identified, the next step is to examine them critically and decide whether or not they are born out by experience. Adlerian therapists such as Marcus and Rosenberg (1998) and Stein (1998) accomplish this through Socratic questioning. This involves challenging the client's beliefs through questions such as: How do you know when a person is adequately intelligent? Have you ever done an intelligent thing in your life? If so, how come? Such questions are aimed at giving the client insight regarding the fact that the beliefs of personal inadequacy are indeed unfounded and that her interpretation of the event in the defining moment that led her to decide that she is stupid was wrong. If the client can arrive at the conclusion that such self-defeating beliefs are not born out by experience, then she can see the need to formulate new beliefs that energize her to perform tasks that are consistent with her personal mission. For instance, her belief that she is not intelligent enough to

complete tasks involving mathematics may be substituted by a new belief that, ‘Experience has shown that I am intelligent and I can accomplish any task that I set my mind to. I therefore choose to take the GRE, get the required score, and obtain admission into graduate school to pursue the degree that will enable me to serve people in the way that I want to.’

Phase 2: Action

6. Setting Goals

Once activities that will enable the client to achieve the stated mission have been identified and the self-defeating beliefs have been revised, the next step is to set concrete goals. Occupational therapists are familiar with setting short term and long term goals (Bruce & Borg, 2002; Creek, 2002; Early, 2000). Goals should be functional, specify observable, measurable behavior, and achievable within a reasonable time frame (Bruce & Borg, 2002; Creek, 2002; Early, 2000). This view, which is familiar in occupational therapy, is similar to the Adlerian view that in order to change a person’s lifestyle, “... small progressive action steps, aimed at overcoming previously avoided difficulties, must be taken, one at a time” (Stein & Edwards, 2002, p. 11). In setting goals, the therapist uses skills in activity analysis to assist the client to set concrete, achievable goals that are consistent with the stated mission. For instance, for the client who wants to go to graduate school, our knowledge of the task of preparing for test taking helps us to assist the client in setting goals such as: “By the end of this week, I will have identified and bought books that I can use to study for the GRE.” “By the end of two weeks, I will have compiled a list of 10 centers where GRE taking skills are taught and I will have contacted at least two of them to find out what I need to do to get into their program.” Such goals are aimed at getting the client to fulfill the prerequisites such as applying for and getting accepted in a graduate program which is the first step in getting her to realize her mission of being a professional who helps other people with their problems.

7. Performing activities to strengthen the newly chosen beliefs

The mainstay of occupational therapy is doing (Reilly, 1962; Sabonis-Chafee & Hussey, 1998). This valuing of doing is consistent with James’ (1977b) disdain for any individual who would just talk and fantasize rather than engage in reality through concrete actions. The same idea is reiterated by Marcus and Rosenberg (1998) who recommend concrete activities as experiments to help dissolve negative imprints of perception of self in the client. This doing takes the form of occupations which have been defined as: “...chunks of culturally and personally meaningful activity in which humans engage that can be named in the lexicon of our culture” (Zemke & Clark, 1996, p. 43).

In the pragmatic conceptual model of practice, activities that are performed by the client both in and out of the clinic are those that enable the client to engage in occupations that lead to a lifestyle that is purposeful and meaningful according to the formulated mission statement. In the example given earlier, the client can engage in relevant activities in the occupational therapy clinic to strengthen the newly established belief that she is an intelligent woman who can accomplish anything she sets her mind into, and therefore is capable of attaining the required GRE score. One such activity may be to construct items that involve measurement and scaling which requires mathematical calculation skills. The client can be engaged in making items such as a bird house or a picture frame, which would require that she plan out the activity, sketch the object in order to have a visual image of what it will look like, calculate its dimensions such that it is proportional, and so on.

8. Evaluation of the cognitive and physical capabilities to perform chosen activities

The client’s beliefs about his or her ability to complete requisite activities cannot be realistically assessed until he or she is observed in action. This is when the therapist can see whether there are physical or cognitive impediments to the client’s abilities. For instance, the therapist may observe that however much the client tries to visualize the object abstractly in order to sketch it, she is not able to do it. This would indicate that the cognitive ability to organize information abstractly in order to complete the task might be impaired. Or it may

be that the client can conceptualize the object but does not have the coordination and manual dexterity to work with the wood to create the required shapes.

Once these difficulties are observed, the therapist and client decide whether to explore solutions to overcome them or adjust the client's beliefs and mission. At this point, other frames of reference can be used to supplement the model proposed in this paper. For instance, the Cognitive/Behavioral Frame of Reference (Bruce & Borg, 2002; Stein & Cutler, 2002) may be used to assess cognitive deficits that may prevent the client from completing required tasks and provide intervention to correct such deficits or compensate for them. Such an intervention may, for example, be "self-talk" to help the client talk herself through the procedures and behaviors needed to complete the task such as listing the number of pieces of wood needed to complete the project, the required shape of each piece, the orientation of the pieces to each other, etc. (Bruce & Borg, 2002).

Once the client learns how to analyze the task through "self-talk" she can visualize the object, sketch it, and calculate the dimensions accordingly. Or the client's cognitive deficits may be due to stress. In such a case, she can be taught self-regulation skills so as to manage stress and be able to concentrate and complete cognitive tasks (Stein & Cutler, 2002). The biomechanical model (Kielhofner, 1997) may be used to assess physical functioning deficits such as lack of coordination and/or strength and provide intervention to help the client overcome the deficits. If the difficulty cannot be addressed through training or any other physical, cognitive, or psychological intervention, it may be that the client needs to change beliefs about what he or she can or needs to be able to do in order to lead a purposeful and meaningful life. Thus, the treatment process goes back to the belief establishment phase.

9. Commitment

Once activities necessary for achievement of the personal mission by the client have been identified, beliefs that support performance of such activities have been clarified, and short and long term goals have been established, the client must commit to perform the activities regularly so as to progress towards the personal mission. These activities must be performed both in the clinic with the therapist and when the client is on his or her own. Such commitment is achieved by establishing a contract between the therapist and client. This is important because it is the beginning of the training process for the client's "will" so that he or she can learn to choose the right goals and to persist in attempts to reach stated objectives (Assagioli, 1973). According to Assagioli (1973), such willful choice and struggle in volitional activity integrates a person, which means that through such experience, one feels more whole and in balance. The therapist must teach the client that such will is established through consciously making choices every day and every moment of his or her life. Such choices are the building blocks of self-creation which occurs from the inside out (McGraw, 2001).

Phase 3: Appraisal of consequences

10. Evaluation of progress towards personal mission

It is recommended that the therapist and client meet on a weekly basis to evaluate what activities have been performed and what the consequences have been. The goal is to demonstrate to the client that there is a connection between activities and the consequences. In the short term, scores in the AIIIOT may be used to assess progress in terms of performance of chosen activities, and satisfaction with performance. In the long term, the more enduring consequences are examined. As McGraw (2001) argues, every decision a person makes has consequences. The consequences may be external or internal. External consequences might be a significant other person admiring the client's work. This indicates to the client that his or her work is valued in his or her context because it has an effect on that context (environment). An internal consequence may be an increased sense of confidence. In our earlier example, completing a series of chosen activities over the week might affirm the client's newly created belief that she has the skills to accomplish her goals.

At this point, the therapist and client examine the consequences of the client's activities carefully and if they are what was expected, therapy continues until the client is confident that she or he can accomplish the mission. In the example, this may be when the client gets admitted in the graduate school. At this point, therapy is terminated. If on the other hand, the consequences are not what was expected or desired, the client and therapist may need to revisit the client's beliefs and re-initiate therapy from there. In the example given in this paper, if after studying hard the client fails to attain the required GRE score, then in collaboration with the therapist, she may need to reassess whether going to graduate school is really the only way that she can lead a purposeful and meaningful life. May be there are other ways she can achieve the goal of helping other people solve their problems. Or possibly there are graduate programs that she can be admitted into without the need for GRE. She may therefore need to adjust her beliefs about her worth, and what makes her a valued human being. Whatever the outcome of therapy however, in accordance with the complex dynamical adaptive systems theory, the human being as a system is postulated to be sensitive to initial conditions (Arndt & Bigelow, 2000; Bolland & Atherton, 1999; Campbel, 1993; Whiting, 2001). This means that our interventions may have an effect on the client's life that we can never fully predict. Understanding that the client's mission statement is an attractor however, can give us confidence that, even though we cannot predict specific changes in his or her life as a result of our intervention, the changes made are likely to be positive since her mission in life (attractor) is positive.

Limitations of the model

This model is most appropriate for use with adolescent and adult clients who may be physically and/or emotionally impaired but are cognitively intact. The example given of the young woman who wants to go to college and become a counselor is specifically chosen to emphasize this focus. The model can however be used to help even those who have cognitive difficulties to live a meaningful life. For example, a person who is very close to a cognitively impaired client such as a spouse or a loving sibling may be able to help the therapist articulate a possible mission statement for the client and design goals and activities accordingly. The resulting therapeutic intervention may still prove to be more meaningful than use of activities without trying to take into account what makes the client's life purposeful and meaningful. The model is applicable cross-culturally since it is client-centered and the individual client determines, in collaboration with the therapist, activities and interventions that are important to him or her according to his or her unique background.

Recommendations

It is recommended that the model be tried in practice with cognitively intact adolescent and adult clients and data gathered through type II applied scientific inquiry (Mosey, 1996), to determine adequacy of the guidelines for practice and refine them accordingly. Also, through clinical research, various assumptions and hypotheses of the model need to be tested before adoption of the model for widespread clinical application may be considered.

Conclusion

In this paper, guidelines for practice using "Instrumentalism in occupational therapy: A pragmatic conceptual model of practice" have been outlined. Therapeutic intervention using this conceptual model begins with belief clarification and establishment since beliefs are the basis of using the mind as a tool for adaptation to the environment. Belief establishment begins with a personal mission statement that covers all areas of a client's life. Activities that the client is required to perform in order to achieve the stated mission are identified. The client's beliefs regarding ability to perform such activities are examined, and if not appropriate, are adjusted accordingly. Finally, the client engages in activities that will help him or her live according to established beliefs and the personal mission. Therapy is terminated when the client feels that he or she is clearly progressing towards the stated mission.

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Appendix

Assessment and Intervention Instrument for Instrumentalism in Occupational Therapy (AIIIOT)

When using this instrument, the therapist should find a quiet place where the client can concentrate and respond in detail to all the items without interruption. The client should be given as much time as necessary to respond to all the items in this instrument exhaustively. The instrument consists of four sections. Section (I) is designed to lead the client to formulate a personal mission statement to create a purpose towards which to strive. Section II involves identification of some of the activities to be performed in order to attain the stated mission. Section III evaluates the frequency and perceived adequacy with which the activities are performed, the satisfaction with that performance, and the beliefs about the ability to perform the activities adequately. Finally, in section IV, ratings are added together to give an index of frequency, adequacy, satisfaction, and beliefs about the ability to perform the listed activities.

I. Personal mission statement

The therapist should read the following directions loudly and guide the client to complete the exercise (see Covey, 1990). Imagine that you are attending your own funeral. It is now time to read the eulogy. Write down in detail what you would like each of the following to say about you: a) Family (Father, mother, spouse, son/daughter, sister/brother, cousin, any other family member that you feel close to). b) Friends (one or two close friends). c) Work/professional associate. d) A member of the church or other community organization to which you are affiliated. Now go over what you have written and take a few moments to think about what you imagine each of the people saying about you. These statements represent the kind of person that you would like to be and that you can be. Summarize the statements in a few sentences, stating what you consider to be your personal mission statement. Your mission statement will provide direction towards which you will strive from now on. The statement should consist of four aspects as identified in the eulogy: family, friends, work/professional life, and engagement in church/community organizations.

II. Identification of activities

For each of the four areas, identify two (2) concrete activities that you will need to perform on a regular basis in order to achieve your mission in life.

A. Family

- 1.
- 2.

B. Social (Friendship)

- 1.
- 2.

C. Work/Profession

- 1.
- 2.

D. Affiliation to church/community organizations

- 1.
- 2.

III. Evaluation

For each of the identified activities, rate yourself on a scale of one (1) to four (4) regarding: a) The frequency with which you perform the activity; b) The adequacy with which you perform the activity; c) Satisfaction with your performance; and d) Your beliefs regarding your ability to perform the activity with desired frequency and adequacy.

Descriptors

Frequency

1=does not perform the activity; 2=rarely performs the activity; 3=regularly performs the activity; 4=frequently performs the activity.

Adequacy

1=I am not able to perform the activity; 2=Performs the activity with difficulty and the outcome is inadequate; 3=Performs the activity with difficulty but the outcome is good if I complete it; 4=Performs the activity easily, is always able to complete it, and the outcome is always adequate.

Satisfaction

1=I am disappointed with my performance of the activity; 2=I am somewhat satisfied with my performance; 3=I am satisfied with my performance but would like to improve; 4=I am happy with my performance as it is.

Belief

1=I do not believe that I am capable of performing the activity; 2=I believe that I can perform the activity but with much help; 3=I believe I can perform the activity with some help; 4=I believe I can perform the activity adequately and independently.

		Frequency				Adequacy				Satisfaction				Belief			
		1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
A. Family																	
1.		---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---
2.		---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---
B. Social (Friendship)																	
1.		---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---
2.		---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---
C. Work/profession																	
1.		---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---
2.		---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---
D. Affiliation to church /community organization																	
1.		---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---
2.		---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---
Scores (x11, x12, x13 x14)		_____				_____				_____				_____			
		Frequency				Adequacy				Satisfaction				Beliefs			
Scores (x21, x22, x23, x24)		_____				_____				_____				_____			

To obtain total scores, add the ratings for each column and put the score at the bottom of the column. These scores are denoted x11, x12, x13, and x14 for frequency, adequacy, satisfaction, and beliefs respectively.

To obtain the scores at the end of the therapy week, have the client rate himself or herself again and add the scores under each column. Denote the scores x21, x22, x23, and x24. The progress made in therapy during the week is indicated by, x21-x11, x22-x12, x23-x13, and x24-x14 respectively.

Comments:

Coping with Stress among Middle-Aged and Older Women and Men with Arthritis

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Abstract

Arthritis is considered a stressful, chronic illness, highly prevalent in our society. Because of chronic, multiple challenges or stressors that people with arthritis experience, the use of stress-coping strategies may be important for counteracting the negative impact of stress among these individuals. The purpose of the present study was to examine the ways in which

middle-aged and older women and men with arthritis cope with stress, including the potential contribution of leisure to stress-coping. To provide a context for this examination, their meanings and sources of stress were identified, as well. This exploratory study used a series of focus groups segmented by gender. The focus group data suggested the prevalence of stress in participants' lives, and living with arthritis was considered a major source of stress, particularly combined with the aging process. Specific common themes of stress-coping strategies identified include: (a) keeping active and busy, (b) exercise/physical activity, (c) educational—gaining knowledge about arthritis, (d) socialization/social support/friendship, (e) spiritual coping, (f) acceptance—acknowledging stress, (g) helping others—altruistic benefits, and (h) leisure as a means of coping with stress. Also, identified were two overarching themes of stress-coping strategies that cut across or tie the above eight specific themes together to broadly and holistically conceptualize core meanings of stress-coping for middle-aged and older women and men with arthritis—(1) leading an active life, and (2) taking control of one's life. Furthermore, the present study suggested some gender differences in stress-coping strategies. Implications of the findings are discussed with respect to the need for multi-dimensional and comprehensive, behavioral and psychosocial interventions for this population group.

Introduction

Arthritis is a major health and psycho-social problem in contemporary society. In the United States, arthritis is the most common cause of disability (National Center for Chronic Disease Prevention and Health Promotion, 2002). It is estimated that about 60 million Americans (almost 20 % of the population) are affected by arthritis, and that nearly 12 million experience activity limitations due to arthritis (National Center for Chronic Disease Prevention and Health Promotion, 2002). In Canada, Health Canada reported in 1996 that the overall prevalence of arthritis among Canadians was 21.1 % for women and 15.7 % for men (Reynolds, Chambers, Badlet, et al., 1992). Globally, arthritis has a world-wide distribution (Lawrence & Sebo, 1988). The prevalence of arthritis is greater among older individuals. In US, the National Center for Health Statistics reported that in 1997 over 36 % of the elderly aged 65 or above was diagnosed with some form of arthritis, while almost 50 % of people in their 70s and 80s have osteoarthritis (OA) [1](Stein, Griffin, & Brandt, 1996). According to 1996 Health Canada report, the prevalence of arthritis increased from 6.3 % for Canadians aged 16 to 74 to 51.2 % for those aged 75 and over (Reynolds et al., 1992).

Arthritis is considered a stressful chronic illness (Melanson & Downe-Wamboldt, 2003). It is known that the persistent pain, joint stiffness, and joint damage of arthritis not only produce substantial physical disability, but also negatively influence numerous aspects of individuals' lives, including functional ability, work, family and social relationships, and psychological status (Escalante & del Rincon, 1999; Yelin & Callahan, 1995; Katz, 1998), as well as lost or reduced independence, uncertainty, and role changes (Melanson & Downe-Wamboldt, 2003). It is also known that the economic burden for individuals with arthritis is significant. For example, Doherty, Brandt, and Lohmander (1998) found that persons with rheumatoid arthritis (RA) suffer from a 50 % drop in their income over a 9-year period. Furthermore, it has been shown that living with arthritis is associated with decreased quality of life (Nadal, 2001).

Huysen and Parker (1998) provided an integrative review on stress and RA. They identified three major factors relevant to the relationship between stress and RA: (a) physiological (stress-related physiological systems that are activated in demanding situations; e.g., immune systems), (b) environmental (situational factors that function as stressors or negative life events such as financial and interpersonal problems), and (c) psychological (individual characteristics such as how persons appraise stressors). They demonstrated the multifaceted nature of stress that individuals with arthritis encounter or experience in their lives.

According to Katz (1998), major stressors that arthritis sufferers typically experience include: pain, fatigue, changes in physical appearance, unpredictability of symptoms, burden of taking care of the disease, medication side effects, and functional impairment. Recently, in their study of older women with RA and OA,

Zautra and Smith (2001) found that depressive symptoms were significantly related to weekly elevations in arthritis pain, negative events, perceived stress, and negative affect for RA patients, and to elevations in arthritis pain and negative affect for OA patients.

Because of chronic, multiple challenges or stressors that people with arthritis experience, the use of effective stress-coping strategies may be important for counteracting the negative impact of stress among these individuals (Smith, Wallston, Dwyer, 2003). Supporting this notion, in their longitudinal study, Evers, Kraaimaat, Geenen, Jacobs, and Bijlsma (2003) found that disease activity in early RA at the three- and five-year follow-ups was significantly predicted by coping and social support at the time of diagnosis after adjusting for disease activity at first assessment, other biomedical and psychosocial factors, and use of medication.

An examination of coping strategies that people with arthritis use to deal with stress has significant implications (Melanson & Downe-Wamboldt, 2003). Aside from its contribution to theoretical advancements, an understanding of the ways in which people with arthritis cope with stress is essential for developing policies and programs to deal with the sources of stress in their lives, and to establish an effective support system to proactively counteract the negative impact of stress on their health. Particularly, an increasing recognition of the behavioral and psycho-social impact of arthritis has led to a growing awareness for the need to incorporate behavioral and psycho-social intervention approaches into biomedical treatment for managing arthritis (Simon et al., 2002). In their discussion of recent advances and future directions in the biopsychosocial assessment and treatment of arthritis, Keefe et al. (2002) emphasized,

“Coping is a topic that is clearly receiving growing attention from arthritis researchers. Perhaps the major reason for this is that data gathered on coping may have important implications for the prevention and treatment of arthritis pain and disability. Many of the psychosocial interventions now being used for persons with arthritis are designed to modify coping strategies initially identified as important in the arthritis coping research literature” (p. 646).

Despite the growth of research on stress, coping, and arthritis, a very limited attention has been given to the potential role of leisure as a stress-coping resource or strategy. Advocating the importance of positive events including leisure as a means of coping with stress, Folkman and Moskowitz (2000a) argued, “historically, coping has most often been evaluated in relation to its effectiveness in regulating distress... What has been underrepresented in coping research is an approach that looks at the other side of the coin, an approach that examines positive affect in the stress process” (p. 647). Research needs to be carried out to understand “the coping processes that people use to generate positive affect in the midst of stress” (Folkman & Moskowitz, 2000a, p. 652). The experience of positive events (e.g., getting together with friends) also potentially helps to generate positive meaning in the midst of stress (Folkman & Moskowitz, 2000a). One of the important sources that contribute to generating positive affect (including enjoyment, happiness, and hope) and meaning (e.g., assuring preciousness of life), while people with arthritis experience stress, appears to be enjoyable and meaningful leisure pursuits. In fact, leisure, stress, and coping research represents an evolving and maturing area of inquiry in the leisure research field (see a special issue of *Leisure Sciences* on leisure, stress, and coping, edited by Iwasaki and Schneider, 2003).

Purpose of Study

The purpose of the present study was to examine the ways in which middle-aged and older women and men with arthritis cope with stress, including a specific attention being given to the potential contribution of leisure to stress-coping. To provide a context for this examination, their meanings and sources of stress were identified, as well. As an exploratory study, a series of focus groups was conducted to gain an understanding of stress-coping strategies from the perspectives of participants themselves. The use of qualitative

methodologies such as focus groups, interviews, or case studies has important implications for advancing an understanding of the ways in which persons with arthritis cope with stress. However, in comparison to the popularity of quantitative methods, very little attempt has been made to employ qualitative methods in arthritis and coping research (Turner, Barlow, & Ilbery, 2002). Discussing future directions in arthritis research, Keefe et al. (2002) suggested that although qualitative methodologies are demanding and time-consuming, “this type of research can potentially lead to new insights into the nature and process of coping” for people with arthritis (p. 646). The present study focused on examining middle-aged and older persons since, as noted earlier, arthritis is substantially more prevalent among older than among younger individuals. Due to the course and prevalence of the disease and all the other losses associated with the aging process, it is very common that older persons with arthritis often feel helpless and ultimately depressed (Nadal, 2001).

Another important concept that should be given attention in arthritis and stress-coping research is gender. It seems inappropriate to assume that effective ways of coping with stress are identical for women and men with arthritis. There appear to be gender differences not only in the experience of pain, disability, and mood, but also in the use of particular coping strategies. For example, Keefe, Lefebvre, Egert et al.’s (2000) findings highlight the salience of gender in understanding pain and disability associated with OA—women experienced significantly greater levels of pain and physical disability and showed more pain behavior than did men. In their several daily-diary studies of people with arthritis, Keefe, Affleck, and colleagues (Affleck et al., 1999; Keefe et al., 2001) found that the average daily pain of women was 72 % greater than for men, and that women used more emotion-focused coping (e.g., venting emotions, seeking spiritual comfort) than did men, while men showed a significantly greater increase in negative mood the day after a day of high pain than did women. McEwen and Stellar (1993) suggested that gender may interact with situational factors such as controllability to produce significantly different responses to stress. Recently, in her study of RA inpatients, Knotek (2001) found that the increase of anxiety, anger, and depressive symptoms associated with the lasting effect of pain feeling was steeper for older (rather than younger) patients and for female (as opposed to male) patients. She also found that fatigue, worry, and relationship stress in home and family settings grew with the duration of pain, but more for female patients than for male counterparts. Furthermore, according to Turner et al. (2002), not only is the use of qualitative methods in arthritis and coping research rare, but also qualitative research on persons with arthritis focuses mainly on the experiences of women—“no studies have focused solely on the experience of men living with OA” (p. 285). Turner et al.’s point justifies the need for conducting a qualitative study focusing on both females and males with arthritis. Although there appear to be common stressors (such as illness-specific stressors) experienced by women and men with arthritis, differences in socialization processes, expectations, and social roles between women and men may play a role in explaining gender differences in the meanings and sources of stress and the ways in which women and men with arthritis cope with stress. Consequently, in the present study, the composition of focus groups was based on gender of participants to allow for gender-based analysis.

Coping with Stress for Individuals with Arthritis

It is increasingly recognized that stress and coping with stress are important concepts in understanding how persons deal with or adjust to arthritis. Stress is often considered a primary cause of disease flares for persons with arthritis (Affleck, Pfeiffer, Tennen, & Fifield, 1987; Keefe et al., 2002). It has been found that stress has a significant relationship with disease activity for arthritis patients. For example, in their longitudinal study of 100 RA patients, 90 OA patients, and 90 healthy controls, Zautra, Hamilton, Potter, and Smith (1999) found that both the RA and OA patients showed greater clinical ratings of disease activity during a week of high stress than during a baseline, low-stress period.

To deal with this disease, it has been suggested that individuals living with arthritis use various coping strategies. Pain-specific coping questionnaires have been developed to assess multiple facets of pain coping, such as the Vanderbilt Multidimensional Pain Coping Inventory (Smith, Wallston, Dwyer, & Dowdy, 1997).

The instrument identifies 11 distinct coping strategies: planful problem solving, positive reappraisal, distraction, confrontative coping, distancing or denial, stoicism, use of religion, self-blame, self-isolation, wishful thinking, and disengagement. However, the need to examine stressors other than pain for arthritis patients is increasingly recognized (e.g., Katz, 1998).

It has been shown that the use of social support may be effective in coping with stress among persons with arthritis. For example, Penninx et al (1997) found evidence for the buffering effect of social support—emotional support “mitigated the influence of arthritis on depressive symptoms” (p. 393), while Tak (1998) found that perceived social support significantly predicted life satisfaction of older women with OA. Another key coping resource may be the role of self-efficacy (i.e., confidence in one’s ability to successfully execute and accomplish a given task, Bandura, 1977) in dealing with stress. There is evidence that self-efficacy may function as a mediator or moderator of pain, disability, and psychosocial health status among people with arthritis (e.g., Rhee et al., 2000; Shifren, Park, Bennett, & Morrell, 1999; Miller & Cronan, 1998). Other coping strategies that may be effective in managing stress experienced by people living with arthritis include: (a) problem-focused or confrontive coping (Hermann et al., 2000; Melanson & Downe-Wamboldt, 2003; Katz, 1998), (b) relaxation strategies (Affleck et al., 1999; Keefe et al., 2001), (c) spiritual coping (Keefe et al., 2001), (d) optimism (Affleck, Tennen, & Apter, 2001), (e) positive thinking (Ravicz, 2000), (f) mood-regulation (Hamilton, 2001), and (g) exercise/physical activity (Focht, Ewing, Gauvin, & Rejeski, 2002).

It is important to emphasize that there is evidence to suggest the effectiveness of psychosocial or cognitive-behavioral interventions for arthritis (e.g., Keefe et al., 1990; Keefe, Caldwell, et al., 1996; Keefe et al., 1999; Rhee et al., 2000). For example, in Parker et al.’s (1995) study, persons with RA received a comprehensive cognitive-behavioral stress management protocol that incorporated a variety of components such as relaxation training; methods for identifying stressors and life goals; strategies for managing pain, mood, and interpersonal relationships; and specific strategies for managing stressors typical of RA. Recent studies have reported the effectiveness of novel stress management approaches including emotional disclosure (disclosing troubling thoughts and feelings about a traumatic experience; Smyth, Stone, Hurewitz, & Kaell, 1999) and the use of humour or laughter (Nakajima, Hirai, & Yoshino, 1999; Skevington & White, 1998) among arthritis patients.

As noted earlier, qualitative methodologies have rarely been used in arthritis coping research (Keefe et al., 2002). To represent such a rare study, Romer (2000) used a qualitative approach to explore the stress-coping process of older women with OA. Her content analysis suggested that the stressors associated with OA involved a wide range of physical, psychological, and social aspects of life, while pain, disability, and dependence on others were identified as major stressors. The majority of the participants appraised living with OA as stressful in terms of both actual loss and potential loss in the future. Consequently, living with OA evoked negative emotions such as anger, frustration, discouragement, fear, and helplessness. In order to manage the stressors, the respondents used a variety of problem-focused and emotion-focused (palliative) coping strategies.

Although it has been given only scant attention in arthritis and coping research, the experience of positive and meaningful life events such as leisure pursuits appears to function as a means of coping with stress for persons with arthritis. In their study of individuals with RA and OA, Zautra, Burleson, Matt, Roth, and Burrows (1994) found that persons who experienced greater numbers of positive events felt less depressed than persons who experienced smaller numbers of positive events. Folkman and Moskowitz (2000a) emphasized that meaningful positive events such as leisure may act as “breathers” from stress, “sustainers” of coping effort, and “restorers” for persons who suffer from serious chronic illnesses such as arthritis.

In summary, the current literature suggests that the use of coping strategies seems important for people living with arthritis in effectively managing stress. Although a variety of resources or strategies have been identified or shown to act as a means of coping with stress, it is not entirely clear how or in what ways these individuals deal with stress from their points of views. Better understanding their insights into the specific ways in which they manage stress is essential not only to theoretical development, but also to rehabilitation and intervention purposes. Therefore, it is important to conduct an in-depth study to directly examine how or in what ways people with arthritis cope with stress from their perspectives. Furthermore, given that there has been very limited evidence for the contribution of leisure to stress-coping despite its potential, it is also important to examine such contribution.

Methods

In order to explore the meaning and experience involving the use of stress-coping strategies for middle-aged and older women and men with arthritis, the present study adopted a qualitative method. Specifically, this study used focus groups segmented by participants' gender. It has been shown that focus groups are an effective method to obtain in-depth information about a concept or issue and to describe and explain people's experiences in practical and efficient ways (Madriz, 2000; Krueger, 1994; Krueger & Casey, 2000). Rather than being predetermined or controlled by hypotheses and existing measures of stress-coping (which are often criticized as based on male normative standards), the use of a qualitative method such as focus groups provides an opportunity to better understand people's perspectives about their experiences and meanings of stress-coping. Openness and flexibility in discovery expressed by actual words of individuals are strengths of such methods. Furthermore, because focus group discussions bring forward people's experiences and offer a social context for meaning-making, they more readily allow for an analysis of gender (Madriz, 2000).

As an analytical framework, phenomenology was adopted in this study. A phenomenological perspective focuses on "what people experience and how they interpret the world" (Patton, 1990, p. 70). Also, Schutz (1970) suggested that phenomenology focuses on the ways in which members of society experience everyday lives and "how the social world is made meaningful" (Gubrium & Holstein, 2000, p. 489). In the present exploratory study, the focus was on describing and interpreting the meanings involving the use and experience of stress-coping among middle-aged and older women and men with arthritis and, then, looking at similarities and differences in their experiences and meanings that could be attributed to gender.

Participant Recruitment and Focus Group Procedures

Participants represented a sample of individuals who had attended an arthritis self-management program [2] offered in a western Canadian city. Two approaches were used to recruit participants. First, one research team member (the second author of the paper) attended a meeting of the program, and explained the purpose and procedure of the study both orally and by distributing a handout. Confidentiality and anonymity of information to be collected were explained to potential participants, as well. Those individuals who were interested voluntarily signed up for a focus group session. Second, a list of individuals who had attended the arthritis self-management program was obtained from the program coordinator only for the research purpose. A research assistant called each individual to explain the nature and procedure of the study and ethical issues, and some people voluntarily agreed to participate in a focus group session. The criteria for being participants included: (a) individuals had been diagnosed to have some form of arthritis, and (b) the individuals were 40 years of age or above. [3} Attention was also paid to ensuring that both women and men were recruited to

participate. Twenty-six individuals who met the above criteria and agreed to participate engaged in one of the three focus groups: (a) women only group (9 women), (b) men only group (7 men), and (c) mixed gender group (5 women and 5 men).

Each focus group session took place at a focus group facility of a local research firm. An experienced professional moderator facilitated all of the focus groups. The moderator followed a focus group questioning route (Krueger & Casey, 2000) developed by the research team and guided by the research objectives. The questioning route outlined opening comments about the topic of stress, introductory questions to engage the participants in the topic, transition questions related to evaluations of stress, key questions on the causes of stress and coping strategies, and ending questions to summarize the discussions and confirm main points (see Table 1). At the conclusion of each focus group, the participants completed an exit questionnaire to provide socio-demographic background information. They were thanked for their time and contribution to the focus group and each was given a \$50 honorarium. Each focus group lasted about 90 minutes as planned. The research assistant transcribed verbatim the conversations of the focus groups. For the mixed gender group, the voices of females were noted as (f), and the voices of males were identified as (m) in the transcriptions.

Table 1. Outline of focus group questioning route and protocol

<p>Opening Comments Welcome and statements regarding the purpose of the study, focus group procedures, and ethical issues.</p> <p>Opening Question Please tell us a little bit about yourself.</p> <p>Introductory Question Stress is something you hear a lot about these days because many people feel stressed. When thinking about your daily life, what does stress mean to you?</p> <p>Transition Questions Is stress a negative factor in your life? If so explain how it is negative. Is stress a positive factor in your life? If so in what ways it is positive.</p> <p style="padding-left: 40px;"><u>Sub-probe</u>: What is it about stress that makes it good or bad?</p> <p>Key Questions What are the things that make you stressed?</p> <p style="padding-left: 40px;"><u>Sub-probe</u>: (a) Would you say it is primarily one thing that causes you stress or is it a number of different things added together? (b) What about any health concerns you may have? (c) Anything else that makes you feel stressed?</p> <p>What are the ways or things that you do or use to help you deal with stress in your daily life?</p> <p style="padding-left: 40px;"><u>Sub-probe</u>: (a) What are your typical ways of coping with stress in your life? (b) What role, if any, does leisure play in helping you deal with stress? (c) Would your thoughts change if you were thinking about vacations and/or holidays (alone and/or with other people)?</p> <p>Ending Questions All things considered, what would you say is the major cause of stress in your life?</p> <p>Of all the ways of dealing with stress that we've talked about tonight, which have you found to be most useful or effective in your life?</p>

Data Analysis Procedure

Phenomenological data analysis was conducted. The principal researcher (i.e., the first author of this paper) and the other researcher (i.e., the second author of the paper) individually identified statements, separately for women and men with arthritis, and listed every significant statement relevant to the phenomenon (i.e., “horizontalization” of the data). Each statement was treated as having equal value (Moustakas, 1994). In the next step, these statements were then grouped or clustered into themes or meaning units, separately for women and men, by removing repetitive and overlapping statements (Creswell, 1998). These meaning units were formulated by reflectively reading and re-reading the full transcripts to ensure that the significant statements were consistent with the original context. The researchers individually engaged in this process to assess whether anything was not accounted for in the clusters of common themes, and to ensure that the proposed clusters did not include interpretations that exceeded the original context of the data (Riemen, 1986). This process resulted in a refinement of the theme clusters, which were then referred back to the original descriptions for further validation.

The principal researcher carefully reviewed the common theme clusters and summary statements that were individually developed in the previous steps. Consistencies between the two researchers’ analyses were retained as overall themes. The principal researcher dealt with divergent analytical aspects by either incorporating some of them into similar themes, or identifying the others as new themes. As a result of this process, the principal researcher constructed an overall and integrated description of the essences (or “essentials”) of the phenomenon, separately for women and men. This synthesis contained the “bones” of the phenomenon (Patton, 1990).

As a final check on the analyses, the two researchers communicated to confirm that the analysis was appropriately carried out and that the results were consistent with and accurately reflected the focus group data, as well as made a final revision on overall and integrated descriptions of the phenomenon. Finally, the participants were sent a summary of the analyses for their assessment. Those participants who returned their evaluation forms (sixteen, 61.5 %, of the 26 participants) unanimously verified that the descriptions were consistent with the views they expressed during the focus groups and their perspectives on stress and stress-coping.

Results

Focus Group Participants

A record of responses to the participant exit questionnaire is presented in Table 2 for each of the three groups: female only, male only, and mixed-gender groups. Table 2 is provided for descriptive and background purposes only. Participants ranged in age from 42 to 78 (mean = 64.2). Of the seven participants who completed a university degree, six were males. Nineteen (73 %) of the twenty-six participants were retired. Of the seven participants who indicated that their yearly household income was below \$20,000, six were females. Regarding race, eighteen (69 %) of the twenty-six participants identified themselves as Caucasian. As for the type of arthritis, seventeen participants (65 %) were diagnosed to have osteoarthritis (OA), while seven participants (27 %) had rheumatoid arthritis (RA). One participant was diagnosed to have both OA and RA, and one person did not indicate the type of arthritis. The participants represented a wide range of time of been diagnosed with arthritis (from 1 to 50 years). The perceived severity of arthritis (on a scale of 1 = mild to 5 = extremely severe) ranged from mild to extremely severe. Twelve (46 %) of the twenty-six participants rated medium severity (= 3), while six of the eight participants who rated 4 or 5 (extremely severe) were females. Perceptions of arthritis-related pain (on a scale of 1 = mild to 5 = extremely severe) ranged from 2 to 5. Of the five participants who rated their perceived pain as “extremely severe,” four were females.

Table 2. Summary for socio-demographic characteristics of the participants

	Female Only Group	Male Only Group	Mixed Gender Group	
			Females	Males
Age: 40-44	0	0	1	1
45-49	1	0	0	0
50-54	1	0	0	0
55-59	1	2	0	1
60-64	2	0	1	0
65-69	0	3	3	1
70-74	3	2	0	1
75-79	1	0	0	1
Highest Level of Education:				
Graduate degree	0	1	0	0
Bachelor degree	1	2	0	3
Some degree (R.N., R.I.A.)	1	2	1	1
Business/trade certificate	0	1	1	0
Teaching certificate	0	0	1	0
Grade 12 & some post-secondary education	0	0	1	0
Grade 12	4	1	0	1
Less than grade 12	3	0	1	0
Marital Status:				
Married	3	5	2	4
Single	1	0	1	0
Divorced or separated	1	2	2	1
Widowed	4	0	0	0
Occupational Status:				
Retired	6	6	4	3
Unemployed	0	1	0	0
Household worker	1	0	0	0
Employed, full-time (35 hrs or more/wk)	2	0	0	2
Employed, casually (less than 10 hrs/wk)	0	0	1	0
Yearly Household Income:				
Above \$100,000	0	2	0	0
\$90,001-100,000	0	0	0	1
\$80,001-90,000	1	0	0	0
\$70,001-80,000	0	1	0	1
\$60,001-70,000	0	0	0	0
\$50,001-60,000	0	2	1	0

\$40,001-50,000	0	0	0	0
\$30,001-40,000	0	1	0	2
\$20,001-30,000	2	1	0	0
\$10,001-20,000	5	0	1	0
Below \$10,000	0	0	0	1
Missing	1	0	3	0
Race:				
Asian	0	0	0	1
British	1	0	0	0
Canadian	2	0	0	1
Caucasian	4	6	5	3
English	1	0	0	0
W.A.S.P.	0	1	0	0
Missing	1	0	0	0
Type of Arthritis:				
Osteoarthritis (OA)	6	6	2	3
Rheumatoid Arthritis (RA)	2	1	2	2
OA & RA	0	0	1	0
Missing	1	0	0	0
Years Diagnosed with Arthritis:				
1	0	1	2	0
1.5	1	0	0	0
2	0	1	0	0
3	1	1	0	1
3.5	1	0	0	0
4	2	0	0	0
5	2	0	1	1
6	0	0	0	1
7	0	1	0	0
8	1	1	0	0
10	0	1	0	0
15	0	0	0	1
20	0	0	1	1
30	0	1	0	0
38	0	0	1	0
50	1	0	0	0
Perceived Severity of Arthritis:				
1 = mild	0	1	0	0
2	3	1	0	1
3	4	4	1	3
4	1	1	4	0
5 = extremely severe	1	0	0	1

Perceptions of Arthritis-Related Pain:				
1 = mild	0	0	0	0
2	2	2	0	2
3	3	2	2	1
4	2	2	1	1
5 = extremely severe	2	0	2	1
Missing	0	1	0	0

In the following section, the participants' descriptions about meanings and sources of stress will be summarized, and then, key themes of coping with stress will be identified and described according to gender-based analyses.

Meanings and Sources of Stress

When asked what stress meant to participants, their responses appeared to suggest that stress is a reflection of their lives. For one female with arthritis, stress means "just getting through the day," while one male with arthritis emphasized, "stress in my opinion is the biggest factor" in his life. That male described stress as "all a package," referring to the effect of stress on his "physical and mental well-being," his entire "body," "diet," and "lack of exercise." For another female, stress means "get[ting] teary and tired," and another male noted, when "I'm stressed out, I don't seem to be able to concentrate like I normally can." For one man, stress means "unknown." "Most stressful situations are just the unknown. It doesn't matter how difficult the problem is; it's the unknown that makes it stress. Once you get a handle on things, stress goes away."

Many participants equated stress with arthritis-related problems or issues such as "taking longer to do things" (female), "the inability to do things the way you used to" (female), the effect of "weather" (male), "delay, frustration, and short temper" (male). One female pointed out, "there's been a lot of changes in my life since I was diagnosed" with arthritis. One male summarized, "the main thing is anything to do with arthritis."

With respect to negative and/or positive aspects of stress, two men and one woman with arthritis did not think stress could be positive at all—"not very comfortable, feel depressed" (male), "get furious" (male), and "you fly off the handle really quick" (female). Many participants described how stress negatively affects their cognitive functioning and behavior—"frustration" due to physical inability (female); "can't sleep" (male); "forgetful" (male); "you don't think clearly when you're under stress" (female); "stress makes me forgetful, what I'm doing, where you've put things, what you have to do" (female).

On the other hand, many individuals (particularly, women) with arthritis agreed that stress could be positive. It could be considered as "a motivator" (male); something that "push[es] you to overcome the difficulties" (male), "pushes you out instead of staying in" (female), or "make[s] you be more aware of yourself, aware of things that are going on around you" (female). "If you stop and think and realize that you're under stress and you analyze what's made it that way, then you can make some changes that are positive" (female). "It [stress] makes you change. I had to learn how to do things differently" (female). Other positive aspects of stress raised by females include: "it [stress] helps you get things accomplished," and boosting "self-confidence" once "getting things done."

When asked to identify main causes or sources of stress, the majority of the participants agreed that living with arthritis is a major stressor, particularly combined with the aging process, as summarized by one female—“As you get older, between age and arthritis you can’t do the things that you used to do. That bothers me more than anything.” Arthritis-related “pain in back and hips and in knees ... bother” them (female & male), while many indicated that they are “limited and restricted” because of arthritis. Living with arthritis was considered “a nuisance” (male), and made some males “inconvenient” and even “very awkward.” Some women and men were “forced to leave a job that [one] loved very much,” and others were “worried” about the fact that “it’s not going to get better” (female)—“I know there’s no cure... I’m incapacitated to some extent and with no hope” (male).

In contrast to these *typical* views, one female suggested a different point of view—“I don’t think that the arthritis itself causes me the stress. It’s when I take on too much, I expect too much of myself and I think that’s it.”

The next most common source of stress mentioned was family issues/problems. Note that the average age of all the respondents was about 65 years and most were retired, yet many were still troubled by family matters (e.g., “worrying about my children,” “illness in the family”)—“I have 3 kids still at home... There’s always that mix going on about how far you’re going to help them” (female). Many men felt out of control over their families (“the family can create a lot of stress because you can’t lots of times control them”), while one male lamented the lack of understanding about his pain in his family.

“At work you can make a decision and change it but at home you can’t necessarily convince your kids you should be doing this” (male).

“My family, they don’t understand my situation. Seems to them I’m only joking because I always say that I have pain here. But they don’t feel what I’m feeling this way. There’s nothing visible for the people. ‘You look OK.’ They don’t know what you’re feeling inside” (male).

Other causes/sources of stress discussed include financial (“lack of money ... money is always a stressor,” male) and job-related matters (e.g., “a bad situation at work where there’s a lot of favouritism and nepotism,” female; “you have to get this building in operation and everybody’s leaning on your shoulder,” male).

“First problem, it was the money. I don’t have any income as of now. I tried for disability, but they deny. They said it’s not severe and it’s not prolonged. I said in the letter, ‘Did you tell me this was not severe? Can you feel what I feel?’ ” (male).

Furthermore, some participants raised loneliness (e.g., “living alone,” female), “too many obligations” (female), and “dealing with difficult people” (female) as other sources of stress.

“I’m suffering from stress from being lonely, my relationship breakdowns and stuff like that. I suppose I’m suffering more stress from loneliness than I am from arthritis” (male).

“I guess the major cause is too many obligations, feeling like you have to take on everything that somebody asks you to do or you think you need to do. You have to learn to say ‘No,’ which is hard because I’ve always looking after everybody” (female).

In the next section, by comparing descriptions of coping with stress for women and men with arthritis, results of gender-based analyses are provided. The focus group data yielded a number of stress-coping strategies that were common to both women and men, while others were unique to one informant group or

the other. In this section, common themes are presented first with a description of the gender-specific themes to follow.

Common Stress-Coping Methods for Middle-Aged and Older Women and Men with Arthritis

Eight common themes of coping with stress emerged from the focus group data: (a) keeping active and busy, (b) exercise/physical activity, (c) educational—gaining knowledge about arthritis, (d) socialization/social support/friendship, (e) spiritual coping, (f) acceptance—acknowledging stress, (g) helping others—altruistic benefits, and (h) leisure as a means of coping with stress.

Keeping active and busy. Many female and male participants described the importance of keeping oneself busy and active as a means of coping with stress. Examples included being involved in group or individual activities, just going out, “volunteer work,” and “doing something every day”—“Being interested in something, being active, keeping busy, and enjoying something” (male). These help to “keep my mind off of things” (female) or “keep your mind occupied” (male).

“I do handicrafts. I do Meals on Wheels when they need me. I play bridge, and I continue to go to our seniors group as often as I can. That’s keeping busy” (female).

“I lead a very active life. I’m quite involved in two senior’s groups in our area and the bridge group at church. I aquacize a couple of times a week, so I keep fairly busy” (male).

“I try to go out just about every day, whether it’s just grocery shopping, or I’ll meet a friend for lunch. [Moderator: How does that relieve your stress?] I think just going out and being with other people, not even necessarily talking to them, but realizing that you’re part of this whole universe, you’re not isolated. That helps me” (female).

“I’m involved with my church. And, I read and I find that I do things to keep me busy, whether it’s going out for lunch with my friends or playing bridge or whatever. So I try to keep as active as I can” (female).

“You have to keep busy and not sit around and think about whatever stresses there might be around you. It certainly helps to get your mind off of it by doing something. Doesn’t have to be an awful lot, just meet someone for lunch, for example. You gotta go somewhere and do something, you just can’t sit there” (male).

Exercise/Physical activity. A number of female and male participants purposefully engaged in some form of exercise or physical activity in order to cope with stress. They suggested that the use of exercise/physical activity for this purpose generates other related benefits such as: enhancing self-esteem, relaxation, facilitating a good night’s sleep, feeling good, health benefits, social benefits (e.g., not feeling isolated), pain relief, and taking mind off of problems.

“I do get on my bicycle downstairs and I try pedal that, and I start at 5 minutes and then I go up to 15 minutes a day and keep myself going. I feel proud of myself when I get off it because I managed to do it” (female).

“Exercise. It really helps relax you; you sleep a lot better. My husband and I usually go out for walks late at night before bedtime. It does make you feel a lot better. [Moderator: So you do that to cope with stress?] Yeah, we do it consciously” (female).

“I go to the Wellness, there are light weight machines, treadmill a little. I work out at least 3 times a week for a good hour. I tough this out, then shower and that makes a difference.” (male)

“I take physical activity classes a few times a week. You’re with other people with arthritis and you talk to them and you don’t feel as isolated. And you’re helping your body by doing range of motion exercises. One class is on the land, one is in the water, and in-between I do skating. And I go swimming still. There are changes that take place in your body when you do physical activity. You feel more endorphins and there’s a different pain relief. You feel physically better health” (female).

“I do exercise. When you exercise you have a lot of flexibility, you can move. So your joint will move around. It’s good to move” (male).

“I have a dog that needs me to walk it. I love him so I take him. When I took a course on arthritis, this is one of the things they say, that you should walk. I know I would sit if I didn’t have him to make me go for walks, so he is a plus” (female).

Educational: Gaining knowledge about arthritis

Another common theme shared by female and male participants was educating oneself or gaining knowledge about arthritis—“knowledge is the biggest asset of all” (male).

“Reading about what is happening to you and getting a better understanding of your osteoarthritis or your rheumatoid arthritis, or your cataract surgery, or whatever. Just having the knowledge of what is happening and knowing which road you have to go to deal with it. That alleviates a lot of it. Not knowing is stressful, but once you know, you feel more in control. I think you have to know what kind of problem you have. Find out what kind of arthritis you have, talk to your doctors, and then you can deal with that. Education is so important” (female).

“Talking to other people with arthritis so you don’t feel alone. You know other people have similar problems and that opens your eyes and makes you more aware” (female).

Socialization/social support/friendship. Many female and male participants agreed that socialization with and gaining support from friends and family members are important to effectively cope with stress—e.g., “Quite often if you join a group, you’re with people who have the same problems and this does help” (female).

“I like being in the groups and sharing. I facilitate the suicide grief group at the Y as a leader. And I’ve also been with Compassionate Friends for bereaved parents. Now I’ve joined the arthritis support group. It’s being with other people who have your life experiences that you can share” (female).

“I found it positive once I joined groups and shared the experiences and methods that were being used to try and rectify the problem. It did become positive in that sense, because we attempted as a group first of all to take control, and secondly to find ways and means, individually, to do things to rectify our situation, which I’ve been doing for the past 20 years” (male).

“I have 5 children and 10 grandchildren and I like to spend time with them. I try to get involved with them in different stuff at home and talk to them about the family, because I want them to have the history of my family which I think is very important. And I take them in the summer to ball games and stuff like that and they enjoy that” (male).

“I’m very lucky because I have my daughter and her husband live just 8 houses down from us and their youngest is 9. She comes over for breakfast every morning and then comes after school, so I look forward to that. [Moderator; Right, she keeps you on the ball.] She sure does. And then I have grandchildren that are involved with water polo and I like to go watch their games and their competitions” (female).

Spiritual coping

Another common theme of stress-coping shared by some female and male participants was the use of spiritual or religious aspects—e.g., “my association with the church. Spiritual and associating with people, just to think of something else for a while” (male).

“Every morning I just pray that I’ll get through the day. I try to do contemplation on a regular basis” (female).

“Well, something I do, that’s been a part of my life in the last 3 years, is my hour with Oprah. Takes me into a whole new world, a positive, spiritual, all those good things. And that is my time, I don’t feel anything, I’m really happy. It’s just a beautiful time” (female).

“I like Reverend Schuler on Sunday—Church service from Crystal City. I think he’s a great speaker. That’s my hour to do just what I want. I find it a lot easier than going out to church” (female).

“I would take out any one of my Wayne Dwyer tapes and I’d go to my bedroom where it’s quiet and I would listen to his tapes and meditate. That’s what I’d do when I feel it’s just getting too much. So I find that quiet time” (female).

Acceptance/Acknowledging stress. Some female and male participants raised acceptance of one’s conditions and/or abilities, or acknowledging (rather than ignoring) the fact that they are experiencing stress as a way of dealing with stress:

“If things have piled up on me and I get irritable, settle back and take it easy. Take your time and don’t accept anything more than what you think you can accomplish in a day. I think it has made me slow down and accept that I’m not as young as I used to be, and I can’t do the things that I used to be able to do” (female).

“Recognizing that I have stress and then just giving myself permission to say, ‘This is what it is.’ Once I recognized that I feel that way, pacing myself and then I can read, or I can get out and walk, I can do whatever and then I feel better. Just acknowledging and then doing whatever activities that make me feel better” (female).

“I try to analyze what exactly is causing this stress and if I can do something about it I will. If not, I accept it and take it the way it comes” (male).

Helping others: Altruistic benefits. Several female and male participants suggested that helping others, for example, through volunteering activities (e.g., “I do a lot of volunteering work at nursing homes,” male), helps them cope with stress:

“I volunteer with other seniors in Canada. I find that helps me a lot because you always see somebody that’s worse than you are. You can share experiences and it helps you at the same time. I want to continue doing for as long as I can” (male).

“Confident in what I was doing. For the last 14 years I’ve been working at the Christmas Cheer Board for two months every year and I thought last year, ‘No I can’t do it.’ But I went in and I worked right through it” (female).

“Being with groups—I can help these people because I have a life experience that I never ever wanted but now that I have it. Just to be there and a shoulder for them to lean on. When they say, ‘Thank you for being there,’ it’s a good feeling too. You know you can help them. You just have to be there to let them know they can survive” (female).

Leisure as a means of coping with stress. Most female and male participants agreed that leisure plays an important role in helping them cope with stress (e.g., giving “enjoyment” and “pleasure,” giving “the balance,” “it’s my time,” stress reduction, feeling better physically and emotionally):

“Leisure is very important because it gives me the balance. You have a goal of each day you’re gonna do so much. But in that day I always set aside time for me, it’s my time. I choose times every day for me. I have a soft-bounce trampoline. And it’s so good. It’s my form of exercising, that’s my pleasure” (female).

“I think there’s definitely a link in the relationship between leisure activities and stress reduction” (male).

“The more leisure you do, the better you feel. Less stress, emotionally and physically better” (female).

With respect to specific leisure activities, female and male participants mentioned “reading,” playing music (“I play violin—I forget about everything,” male), doing puzzles, and camping. These activities help them keep their mind off problems or stressors (e.g., pain), have time for oneself, or feel relaxed.

“I like to read books. You get away from yourself. You’re not thinking about anything else. Reading is my biggest one” (male).

“I read. If you get involved in a book, you forget about your pain” (female).

“I play the piano and fight with the cat. When my life seems to be going into a vicious circle, I’ll sit down and I’ll play some music, or I sit down and play with the cat. Just to stop the world from spinning around” (female).

“Playing the piano is something I do just for myself” (female).

“I do the crosswords, that really relaxes me” (male).

“I like to do crosswords, that’s what I love to do. It keeps my mind from getting the senile old age. It’s a good activity for my mind—just gets me out of thinking about things I can’t do” (female).

“We go camping in the summer and I find it really relaxing” (female).

Furthermore, some participants suggested that leisure travel helped them cope with or reduce their stress. Specifically, described were: taking one’s mind off toward outward, being “out in nature,” “see[ing] things in a different perspective which reduces stress,” getting away from responsibilities and stressors, leisure travel as “relaxing” and a way of “feel[ing] refreshed,” and visiting one’s homeland. One man noted that he “didn’t feel [his] arthritis” during his Costa Rica trip, while another man pointed out that visiting his homeland, Philippines, “reduce[d] the pain of [his] arthritis” and “stresses” “because of the weather” and after “chat[ting] with all the people I know.”

“Twice a year, usually in the spring and the fall, I pack up my husband in the truck and we go away somewhere—we’ve been all over. [Moderator; How does that relieve your stress, going on these trips?] You’re seeing something different, you’re doing something different, and I think it does take your mind off it. For me it would be a stress reliever” (female).

“If we go on any kind of travelling, it’s usually a day trip. [Moderator; How does that reduce your stress?] They do. I can forget about my day job. And it’s nice, you just disappear and you don’t have anything to do for a few hours. I like we get away from yourself” (male).

On the other hand, other respondents found travel difficult because of their physical restrictions and their need for extra preparations. For some, money was an issue—they could not afford to travel (most of these respondents, particularly females, had very low incomes); however, a couple of participants mentioned that “I’d love to travel if I had the money to see the world, to see different places.” Interestingly, these comments about constraints associated with travel were raised only by female participants.

“You have to prepare a lot. At least I have to think, how much walking? Is this gonna be uphill? Downhill? What happens if I have to take my glucosamine and chondroitin. There’s all sorts of logistical things you have to think about. But other than that, it can be relaxing, but just a little extra preparation time is required to think things out” (female).

Stress-Coping Methods Unique to Middle-Aged and Older Women with Arthritis

Besides the above common themes of stress-coping strategies for both women and men with arthritis, other strategies were identified only by either women or men.

Positive attitude and thinking/Positive changes in life. Several female participants, not male participants, suggested the role of having a positive attitude and thinking as an important way of dealing with stress—e.g., “I try to have a positive attitude and try to find some joy in each day, whether it’s just a small thing” (female). One woman indicated that “just remember[ing] all these impossible things that I’ve overcome” helps her gain confidence and feel “stronger.”

“Stress. You just seem to flow out of it, if you apply the positive thinking. The power of positive thinking, for me, works, in spite of many types of illnesses that I’ve been given. So taking a positive approach to a stress situation that is negative. You can get good stress out of it” (female).

“I’ve just got to push myself, starting off the day with trying to have a more positive attitude and try to do something each day, saying ‘Get out there and do it, never mind.’ Maybe it’s getting up and riding

that bike for 5 minutes. Getting out of the suite and keeping in touch with people would be good for me” (female).

A couple of females emphasized the power of having a positive attitude to take control over one’s life and make positive lifestyle changes:

“When I was diagnosed with rheumatoid arthritis 38 years ago, my little boy was not quite 2 and I just had a new baby, and I was seeing an internal medicine specialist for my arthritis. And he told me, ‘You’re just going to have to think about yourself and get a maid and what-have-you to look after your family, your house.’ And I thought, ‘No way. I’m just going to take control of my arthritis, I’m not gonna let it take control of me.’ So I decided I was going to have a positive attitude. I find that’s what helps me with my stress” (female).

“I’m still at the stage where I haven’t really accepted the fact that I have osteoarthritis, because I don’t believe it. I believe that I can reverse it and change it if I change my lifestyle, which I’ve done in the last 2 or 3 years—change the way I look at things mentally, physically, change my diet—a healthier way of living. Because that’s really what has caused where I’m at. Initially you have the doctor’s support, you have the medication, but ultimately you have to do it on your own and only I can change what I have in my knees with whatever medication, along with exercise and changing your entire lifestyle, so that you have better health results. I don’t want to wear the label that I have arthritis” (female).

Female-specific leisure activities as a means of coping with stress. Specific leisure activities discussed only by females included: “cooking and baking,” “keeping a journal,” “painting,” “drawing,” “making cards,” and “Christmas decorations.”

“Cooking and baking. That’s one thing that does make me feel good. [Moderator; Sure. You would consider that a leisure activity?] It is in a way, yeah, because I’d rather do that than housework” (female).

“Yes, I guess it [leisure] does. I’m keeping a journal. You just get a lot of things off your chest, what you’re feeling, how you’re feeling. It’s like as if you were talking to somebody and it’s just like a burden shared is a burden lessened” (female).

Other female-specific coping strategies. Other stress-coping strategies mentioned only by females included: pacing oneself, the use of “humour,” prioritizing (“budget[ing] my time to do things that I really want to do”), and doing nothing.

“Pace myself because if I do too much, then . . . That’s what I’m learning to do, spread it out. [Moderator; How does that reduce your stress, like pacing yourself?] Not dwelling on myself. Well I feel better physically and emotionally” (female).

“Try and have some laughs during your life every day, whether it’s a TV show video or a phone. There’s always one particular friend that no matter what’s on your mind they always make you laugh. Phone that friend. Then when I’m really stuck, I have a lot of cartoon books. Herman always makes me laugh” (female).

“When I quit work one of the things I did is, a lot of prioritizing. And, let go of a lot of stuff because you can’t save the world. I think I am less stressed now than I used to be” (female).

“Giving myself permission sometimes to sit and do nothing, which took quite a while. Sometimes you start feeling guilty if you’re not doing anything” (female).

Stress-Coping Methods Unique to Middle-Aged and Older Men with Arthritis

Not thinking about stress. Several men, not women, talked about “not thinking about” stress as a way of coping with stress:

“I go to bed and clear my mind. I just say I’m not going to think about that” (male).

“I think when I feel stress you have to think about it. ‘Oh, God it’s hurting. Jesus I wish I didn’t have arthritis.’ It’s almost like a self-hypnosis. You don’t think about stress. And when you don’t think about it, it’s not there!” (male).

Comparing oneself with less fortunate people. As a mental approach, several men seemed to purposefully compare themselves with less fortunate people; they “wouldn’t trade places” with less fortunate people—“Thinking how lucky you are compared with other people.”

“What helps my stress probably is, you know there are thousands of millions of people on the face of the earth with whom I wouldn’t trade places. When things get really bad, ‘Gee, I’m glad I’m not in a bloody cave in Afghanistan, or in a mud slide, or tornado’ ” (male).

“I just got back from Cuba. And talking of people that are less fortunate than we are, Cubans. Living under a Communist regime is not the biggest blessing in the world. It’s a beautiful country, but very poor people. Would you rather be in Cuba without any arthritis, or would you rather be a Canadian with arthritis? No, I’d rather be here with arthritis. I try to deal with my arthritis here” (male).

Other male-specific coping strategies. Other stress-coping strategies pointed out by men included: asking “Do I care?,” and having “a nice cigar and a nice glass of wine” alongside one’s “fireplace”—“it feels good” and “relaxing.”

“When you find something that really bugs you, I like to think, ‘Well, will anybody care about this in 100 years?’ If I get home and the laundry is not done and the house isn’t done, maybe my wife’s had a bad day. Don’t let it worry me any more. The big thing is, ‘Do I care?’ ” (male).

Finally, there appeared to be male-specific leisure activities that can be used as a means of coping with stress. Specifically, several men talked about sport spectating—e.g., “season tickets” to football games (i.e., “the Bombers”) and watching professional sports on TV (e.g., “NFL football”).

Discussion

Our analyses of focus group data, which contain in-depth and extensive descriptions about stress and stress-coping from the perspectives of our participants, suggest not only that stress is prevalent in lives of middle-aged and older women and men with arthritis, but also that they use a variety of coping strategies to deal with stress in their lives. For some, stress means “just getting through the day” or “all a package” in one’s life; for others, stress means “unknown” or “get[ting] teary and tired.” Although stress is considered primarily negative (e.g., “not very comfortable,” “feel depressed,” “get furious,” “frustration,” “can’t sleep,” “forgetful”), the participants (particularly females) identified the possibility that stress could be positive (e.g., “a motivator,” “push you to overcome the difficulties,” “make you be more aware,” “help you get things accomplished”). For the majority of the participants, a primary source of stress is, in fact, arthritis-related problems or issues such as “pain,” “limited and restricted” physically and behaviorally, “taking longer to do things,” “the inability to do things the way you used to,” and “no hope.” Many agreed that the

aging process exacerbates or aggravates the challenges or problems with arthritis. The other major sources of stress described were family issues/problems, financial stressors, job-related matters, and loneliness.

Coping strategies discussed by the participants represent a wide range of behavioral and psychosocial approaches to manage stress. As described in the results section, the specific common themes of stress-coping strategies identified appear distinct in focus and uniqueness. However, from a broader and more holistic perspective, it seems possible to conceptualize overarching themes that cut across these specific themes. Despite the differences in the focus of each specific theme, the focus group data appear to suggest the existence of overarching themes that tie these themes together to broadly or holistically conceptualize core meanings of stress-coping for middle-aged and older women and men with arthritis.

Overarching Themes of Stress-Coping for Middle-Aged and Older Women and Men with Arthritis

Leading an active life. One such overarching theme is leading an active life. This theme is concerned with all aspects of life including: physical, psychological/cognitive, emotional, social, and spiritual involvements in life. Examples from physical activity illustrate many of these aspects, including social (“You’re part of this whole universe, you’re not isolated.”), physical (“There are changes that take place in your body when you do physical activity. You feel physically better health.”), and psychological such as the enhancement of self-esteem (“Feeling so good about it, feeling so proud”), relaxation (“It helps relax you.”), and peacefulness (“Going for a walk” facilitates “peace and tranquility.”). In their recent review paper, Hurley, Mitchell, and Walsh (2003) concluded that for persons with arthritis “the psychological benefits of exercise are as important as physiological improvements” (p. 138). They identified coping with arthritis as a key factor of “psychosocial sequelae of OA” (p. 139) gained from exercise.

In addition, many participants were conscious of gaining knowledge about arthritis (i.e., cognitive)—“Just having the knowledge of what is happening and knowing which road you have to go to deal with it.” Also, a number of participants extensively discussed the importance of leading an active *social* life—“Talking to other people with arthritis so you don’t feel alone.” One woman described another benefit of leading an active social life—“Going out, you just sort of become part of the whole universe.” Also, some participants talked about the role of spirituality in effectively coping with stress (i.e., leading an active life spiritually)—“Spiritual, contemplation, pray.” Also, accepting one’s conditions and acknowledging stress are considered an element of leading an active life. It appears important to accurately acknowledge one’s conditions and abilities and to realize that life *is* stressful in order to make appropriate choices to lead one’s life to right directions. One female summarized this point, “Recognizing that I have stress and then just giving myself permission to say, ‘This is what it is.’ Once I recognized that I feel that way, pacing myself and then doing whatever activities that make me feel better.”

Furthermore, helping others such as being involved in volunteer activities (i.e., altruistic) is considered one important aspect of leading an active life. For example, one man suggested, “I lead a very active life. I’m quite involved in two senior’s groups in our area, and I do a lot of volunteering work at nursing homes.” It was described that being involved in volunteer activities to help others facilitate one’s confidence and a good feeling. One woman pointed out that “working at the Christmas Cheer Board” helps her feel “confident.”

The role that leisure plays in helping persons with arthritis cope with stress should not be undervalued. In the focus groups, this role of leisure was extensively and often enthusiastically described by many participants. Their descriptions suggested that the constructive use of leisure is not only effective in dealing with stress, but it is also an important component of leading an active life for them. For example, one male noted, “I think there’s definitely a link in the relationship between leisure activities and stress

reduction,” while one female indicated, “Leisure is very important because it gives me the balance.” For her, “leisure is pleasure, so I choose times every day for me.” Another female concurred, “I think you have to have some enjoyment in life. So you try to pick the things that you’d like to do.” One woman emphasized benefits of leisure with respect to stress reduction and physical and emotional health—“The more leisure you do, the better you feel. Less stress, emotionally and physically better.”

Another benefit of leisure discussed was palliative coping through leisure (i.e., a form of a time-out from stressful everyday lives; Iwasaki & Mannell, 2000; Iwasaki, Mannell, Smale, Butcher, 2002 & in press). Speaking of reading, one female mentioned, “If you get involved in a book, you forget about your pain,” while the importance of playing a musical instrument was raised by one man, “I play violin—I forget about everything.” Likewise, one female pointed out, “I play the piano. Just to stop the world from spinning around.” For her, “playing the piano is something I do just for myself.” Talking about cross-words puzzles, another woman suggested, “It’s a good activity for my mind. Just gets me out of thinking about things I can’t do.” Also, participants described that leisure helps them keep their minds off of problems and feel relaxed. For example, one man mentioned, “I just love to go for a walk. It takes my mind off any problems and gets my mind off. And I go anywhere on the river and go fishing. I find it very relaxing.” One female talked about a “nice relaxing bath” as a means of coping with stress, while another female noted, “I do jigsaw puzzles that help to relax.”

In addition, some participants suggested that leisure travel is a means of coping with or reducing stress. As described in the results section, stress-coping benefits of leisure travel mentioned include: taking one’s mind off toward “outward,” being “out in nature,” “seeing things in a different perspective,” “getting away” from responsibilities and stressors, and relaxation. However, it must be pointed out that other participants (particularly, women) felt travel difficult and restricted due to their health problems or concerns.

In summary, regardless of the type of activity that middle-aged and older persons with arthritis engage in for various purposes, one overarching theme of coping with stress appears to be leading an active life. As human beings, individuals with arthritis seem to value the importance of pursuing their lives in a meaningful way. Their behavioral involvements in life, as well as their social, educational, psychological, spiritual, and altruistic involvements, help them gain important meanings in the pursuit of their lives, by affirming the significance and preciousness of living. Thus, their lives as a whole seem to be multi-dimensional and multifaceted rather than one-dimensional. The eight common themes of stress-coping identified represent or illustrate some of the important activities or pursuits that help persons with arthritis generate meanings in their lives. Persons with arthritis, at least, in the present sample, seem to be trying to ascertain the meanings of living with arthritis within their life-world, by actively affirming its implications for self, relationships, lived space and time, embodiment, personal projects, as well as the way in which these sufferers employ the various relevant discourses surrounding these conditions.

In the past, of various coping methods, problem-focused or confrontive coping strategies were found to be most frequently used and perceived to be most effective among individuals with arthritis (Bendtsen & Horquist, 1994; Mahat, 1997; Katz, 1998). A recent comprehensive review of the literature concerning the influence of stress factors on onset and course of rheumatic diseases including RA supported this notion (Hermann, Scholmerich, & Straub, 2000). More recently, in their longitudinal study on older adults with RA, Melanson and Downe-Wamboldt (2003) found that the majority, at all three time periods, most frequently used confrontive coping, and palliative coping (e.g., doing things to take one’s mind off of stress) and fatalistic (e.g., just putting up with it) or supportant coping (e.g., talking to people, spiritual coping) being second and third. The present findings, however, lent support for a much broader notion of leading an active life as an overarching theme of coping that encompasses multi-dimensional and multifaceted ways in which middle-aged and older adults actively deal with stress. Problem-focused or confrontive coping strategies were, of course, contained within this theme; however, descriptions by our participants

emphasized that leading an active life provides them with an opportunity to gain important meanings of life (i.e., meaning-focused coping, Folkman & Moskowitz, 2000ab).

Perceived control over oneself and one's life. Another overarching theme derived from the data is the perception of taking control over oneself and one's life. The eight specific themes of stress-coping identified in the results section seem concerned, at least partly, with the importance of taking control. For example, speaking of the educational dimension of life, one female suggested, "Getting a better understanding of your arthritis. Once you know, you feel more *in control*. Education is so important" (emphasis added). Referring to the social dimension of life, one man mentioned, "I found it positive once I joined groups and shared the experiences and methods that were being used to try and rectify the problem... We attempted as a group first of all to take *control*, and secondly to find ways and means, individually, to do things to rectify our situation" (emphasis added). One's determination and attitude toward taking control are, in fact, very important to effectively deal with stress associated with arthritis, as convincingly described by one female—in response to her doctor's suggestion to be dependent on helpers, she replied, "No way. I'm just going to take *control* of my arthritis, I'm not gonna let it take control of me" (emphasis added).

The notion of taking control over one's life is relevant to other dimensions of life, as well. For example, keeping active and busy through exercise/physical activity is considered one way of taking control of one's life since exercise provides an opportunity to take charge of one's body and experience a sense of control over self. Similarly, through spiritual coping, one is able to take control of her/his life. Meditation and contemplation may allow a person to feel in control of self. Also, acknowledging stress (i.e., acceptance) is a way of appropriately finding out what is causing stress, which is part of taking control over one's life. One male with arthritis suggested, "I try to analyze what exactly is causing this stress and if I can do something about it, I will." Likewise, a sense of freedom and control is involved in volunteering activities to help others since such altruistic activities are, in definition, non-obligated, unlike paid employment. Finally, leisure pursuits provide an opportunity for persons with arthritis to experience a sense of control and freedom because leisure activities typically take place in free or non-obligated time. As described earlier, one female suggested, "Leisure is very important. I always set aside time for me, it's my time. So that's my pleasure."

Indeed, feeling in control is a key aspect addressed in the concept of self-efficacy. There is growing evidence that increases in self-efficacy may be related to positive outcomes of psychosocial and educational interventions for persons with arthritis (Keefe et al., 1999; Lorig, Mazonson, & Holman, 1993; Smarr et al., 1997). Also, new guidelines for the management of acute and chronic pain in OA and RA incorporate building confidence in patients' self-help abilities as an essential element of biomedical and psychosocial treatments (Simon et al., 2002).

Gender-Specific Stress-Coping Strategies for Middle-Aged and Older Persons with Arthritis

Although the present study identified various specific themes of stress-coping common for middle-aged and older women and men with arthritis, as well as two overarching themes of stress-coping, focus group data appeared to suggest that there were also gender-specific stress-coping strategies. For example, the use of positive attitude and thinking or positive changes in life was discussed only by females, not by males. Also, pacing oneself, the use of humour, prioritizing, and doing nothing were described only by women, not by men. In contrast, not thinking about stress, comparing oneself with less fortunate people, and asking "Do I care?" were raised only by males, not by females.

These gender differences in stress-coping strategies may be explained by the differences in gender-specific life circumstances faced by middle-aged and older women and men with arthritis, and by social and cultural factors such as the differences in socialization processes, expectations, attitudes, and identities

between women and men (e.g., gender role orientations). Specifically for older persons with arthritis, Knotek's (2001) study of RA inpatients provided evidence that female (as opposed to male) patients were more substantially affected by the lasting effect of pain in showing a steeper increase of anxiety, anger, and depressive symptoms. An important finding of Knotek's study directly relevant to gender differences in domestic or household responsibilities is that fatigue, worry, and relationship stress in home and family settings due to the lasting of pain were more strongly exhibited by female patients than by male counterparts. Possibly because of *extra* responsibilities or burdens in home, family, or domestic settings more substantially experienced by women than by men, along with economic/financial disadvantages (as shown in the present study) [4], stress and pain (both physical and psychological/emotional) may be more severe and draining for females than for males with arthritis. There has been evidence to demonstrate the salience of gender in understanding pain and disability associated with arthritis—women with arthritis are more likely to experience greater levels of pain and physical disability and show more pain behavior than male counterparts (Affleck et al., 1999; Keefe et al., 2000; Keefe et al., 2001). Similarly, the present study appeared to show that women reported higher levels of perceived severity of arthritis and arthritis-related pain than did men. Specifically, six of the eight participants who rated 4 or 5 (extremely severe) in their perceived severity of arthritis were females, while four of the five participants who rated their perceived pain as “extremely severe” were females.

Thus, it may be assumed that women with arthritis not only are faced with a wider range of stressors including family/domestic and economic/financial stressors than men with arthritis, [5] but they also appear more susceptible or reactive to the exposure to stress either associated or not specifically associated with arthritis than do male counterparts. This assumption does not mean that lives of men with arthritis are not stressful. Rather, it highlights the importance of giving attention to possible gender differences in: (a) the nature, sources/causes, and appraisals of stress between women and men with arthritis; (b) specific life circumstances (specifically, home, family, or domestic settings) faced by women and men; and (c) social and cultural factors such as the differences in socialization processes, expectations, and attitudes/identities between women and men (e.g., gender role orientations). As an example shown in the present study, unlike men with arthritis, many women with arthritis seemed to feel obligated or pressured to “take on everything,” partly because women are *expected* to do so:

“I guess the major cause is too many obligations, feeling like you have to take on everything that somebody asks you to do or you think you need to do. You have to learn to say ‘No,’ which is hard because I’ve always looking after everybody” (female).

Consequently, because of potential gender differences in the nature, sources/causes, and appraisals of stress, stress-coping strategies used by women with arthritis may somewhat differ than ones used by men with arthritis. For example, as shown in the present study, the use of positive attitude and thinking or positive changes in life may be more critical for women with arthritis than for their male counterparts partly due to the need to deal with the stressful nature of their lives, and the need to reconcile their susceptibility to stress. [6] Supporting this idea concerning positive attitude and thinking, Ravicz (2000) showed that replacing negative thinking with positive thinking is a key factor for effective coping among women with chronic illnesses in order not to deplete the immune system, and to lead a more balanced life. Similarly, pacing oneself, journalizing, the use of humour, prioritizing, and doing nothing may play a more essential role in managing such needs for women with arthritis than for their male counterparts. For example, novel stress management approaches such as emotional disclosure (e.g., through journalizing; Smyth et al., 1999) and the use of humour or laughter (Nakajima et al., 1999; Skevington & White, 1998) recently advocated by an increasing number of researchers, may be more helpful and effective for women with arthritis than for men with arthritis.

In contrast, male-specific stress-coping strategies identified in the present study (i.e., not thinking about stress, comparing oneself with less fortunate people, and asking “Do I care?”) appear to reflect men’s attempt/intention to maintain or restore their self-esteem. Although maintaining self-esteem is important for any individuals to maintain good health and well-being, men may have a stronger desire for the maintenance of self-esteem than for women (Anderson, 1997; Wearing, 1998). Feeling good about oneself (i.e., self-esteem) seems to be one of the most essential and highly valued goals for many men. Although women also value such a goal, many women seem to more frequently and extensively show care for others than do men—Well-being of significant others appears equally important as their own well-being for many women. Because of gender differences in the socialization process and expectations, many women tend to show more concern and care for others. Sometimes, some women might be concerned with others’ needs first rather than their own needs. That is, some women might feel guilty when they try to focus on self. Consistent with this notion, one female in the present study pointed out, “Sometimes you start feeling guilty if you’re not doing anything.” These ideas are related to the social construction of gender roles (Anderson, 1997; Henderson, Bialeschki, Shaw, & Freysinger, 1996).

Furthermore, the present study identified some gender-specific leisure activities as a means of coping with stress. Specifically, cooking/baking, journalizing, painting, drawing, making cards, and Christmas decorations were mentioned only by women, whereas men talked about sport spectating (either live or watching professional sports on TV). There appear to be gender differences in preferences for type of leisure activities as a way of coping with stress.

Implications of Findings

The findings of the present study support the importance of providing multi-dimensional and comprehensive, behavioral and psychosocial interventions for middle-aged and older persons with arthritis, as recommended in the recent literature (see Keefe et al., 2002 for a review). Given the use of a participant-centred qualitative methodology in this study, perspectives of our participants themselves were truly incorporated in the analyses of the data and interpretations of the findings. Broadly, it appears important and useful to give attention to the two overarching themes of stress-coping identified (i.e., leading an active life and taking control of one’s life) in intervention programs for middle-aged and older individuals with arthritis. More specifically, the eight specific themes of stress-coping derived from the focus group data seem to provide some of the key clues or insights into the process of how intervention programs help and facilitate middle-aged and older persons with arthritis to lead an active life and take control of their lives. These themes deal with various factors/dimensions that can potentially be incorporated into interventions including: behavioral, social, educational, psychological, spiritual, and altruistic. These multidimensional factors appear to represent key elements of comprehensive, behavioral and psychosocial interventions or treatments for middle-aged and older individuals with arthritis.

These suggestions are consistent with recent literature on treatment programs for older persons with arthritis. For example, based on Seligman’s (1975, 1991) theory of learned helplessness, Nadal (2001) developed a treatment program for older individuals with arthritis. The goal of the program is to help those individuals develop a more optimistic explanatory style that will ameliorate depression. According to Seligman, learned helplessness occurs when a person believes that she/he has no *control* over certain events. The program incorporates both psychological treatment and a psycho-educational component, and focuses on patients’ behaviors and beliefs. It utilizes cognitive and behavioral techniques, stress management training, self-care, and psycho-educational instruction to ameliorate feelings of helplessness, hopelessness, and worthlessness. Evers et al.’s (2003) recent findings from their longitudinal study suggested the importance of psychosocial interventions for arthritis patients, as well.

Also, the literature suggests the importance of leading an active lifestyle for older individuals with chronic diseases including arthritis (e.g., Harman, Holliday, & Meydani, 1998). Given that, as demonstrated in our findings, the meanings for leading an active life substantially vary among arthritis patients, it is important to involve patients in the development and implementation of approaches to coping with stress (Melanson & Downe-Wamboldt, 2003). This notion is consistent with recent chronic illness literature that recommends a shift in focus from a compliance model to a shared decision-making model (Thorne & Paterson, 2000).

From practical perspectives, the specific and overarching themes of stress-coping identified in the present study appear to highlight the importance of recognizing and using strengths and resilience of persons with arthritis. This idea is consistent with a recent growth in positive psychology. For example, an increasing number of scholars advocate that it is important to “accentuate the positive” rather than “eliminate the negative” (Berscheid, 2003, p. 44; Larsen, Hemenover, Norris, & Cacioppo, 2003, p. 218-219). Similarly, speaking of positive clinical psychology, Seligman and Peterson (2003) emphasized, “the best therapists do not merely heal damage; they help people identify and build their strengths” (p. 306). These notions seem significantly applicable to helping people with arthritis more effectively cope with stress.

Often, compared to the role of behavioral (such as exercise, nutrition), cognitive, and social aspects of life, the potential of leisure pursuits as a means of helping persons with chronic diseases lead an active lifestyle has been given little attention. However, recently, researchers have begun to emphasize the importance of leisure as a key component of active lifestyle. For example, Folkman and Moskowitz (2000b) suggested that in addition to exercising control over one’s disease, exercising control over other areas of one’s life (including leisure) is an important determinant of counteracting distress under adversity.

In their examination of leisure activities for RA patients, Wikstroem, Isacson, and Jacobsson (2001) found that the patients had given up two-thirds of their leisure activities since the onset of the disease. This giving-up of leisure activities was associated significantly and positively with present disease activity, measured by pain and morning stiffness, as well as significantly and negatively with quality of life. The findings imply that the maintenance rather than the termination of leisure activities appears important to help persons with arthritis ameliorate disease activity and promote quality of life. In her study of older persons with arthritis aged 50 or above, Payne (1999) found that those arthritis patients with a larger leisure repertoire reported significantly greater levels of perceived physical health than those with a smaller leisure repertoire. This finding suggests the importance of engaging in a broader range of leisure activities than a narrower range of leisure activities to reduce the negative impact of disease severity and maintain good physical health. These recent studies briefly reviewed above emphasize the importance of recognizing leisure as one element of intervention or treatment programs for persons with arthritis.

However, the study findings should carefully be interpreted since the study sample represented individuals who were involved in an arthritis self-management program. It was likely that the responses and perspectives obtained from this sample might be somewhat influenced by their experiences in this program. Thus, generalizability of the findings should be further examined in future research. Nevertheless, the richness and extensiveness of data/information about stress and stress-coping described by the participants with the use of a systematic qualitative analysis is a major strength of the study.

Although the present study identified some gender differences in stress-coping strategies for middle-aged and older persons with arthritis, further research is needed to more directly examine such differences in order to suggest relevant gender-specific recommendations for arthritis treatments and interventions. Nonetheless, our suggestions noted earlier about gender differences seem useful and may provide some important insights into the process of gender-appropriate treatment or intervention programs. In future research, in addition to gender, it is necessary to take into account the diversity of society (e.g.,

race/ethnicity, social class, sexual orientations) in order to provide more effective (e.g., culturally appropriate) programs for persons with arthritis.

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[1] Osteoarthritis (OA) and rheumatoid arthritis (RA) are “among the most common forms of arthritis, are chronic in nature, cannot be cured using current biomedical treatments, and can produce high levels of pain and disability. Although OA and RA are considered by laypeople to be primarily joint diseases, RA is perhaps better considered to be systematic because it can affect many organ systems of the body, with resultant potential for significant morbidity and mortality... OA is a degenerative disease that is the result of both mechanical and biological events affecting joint cartilage and underlying bone” (Keefe et al., 2002). In contrast to the prevalence of OA primarily among older people, RA can occur in young adults as well as older adults (National Center for Chronic Disease Prevention and Health Promotion, 2002).

[2] Because of the nature of a sample used, the study findings should carefully be interpreted, as cautioned in the discussion section later in this paper.

[3] The original plan was to have participants with arthritis aged 50 years or above. However, because of the difficulty in locating and recruiting a sufficient number of those older individuals with arthritis, it was decided to lower the age limit of participants to 40. The use of 40 years of age as the cut-point was based on evidence that arthritis is relatively uncommon among individuals aged 40 or under (Felson, 1990). As a result, one person (aged 49) in the female only group, and one female (aged 42) and one male (aged 44) in the mixed group were in their 40s. All the participants in the male only group were aged 50 or above.

[4] Of the seven participants who indicated that their yearly household income was below \$20,000, six (86 %) were females.

[5] Marital status of the participants might have influenced their descriptions of household responsibilities as a stressor. For females only 5 out of 14 (36 %) were married, while for males 9 out of 12 (75 %) were married. Most

male participants thus had the benefit of having spouses share responsibilities for household work., while most females did not.

[6] Interestingly, as shown earlier in the section of Meanings and Sources of Stress, in the present study older females with arthritis more extensively discussed positive aspects of stress than did their male counterparts.
