

## ***The Relationship of Life Satisfaction with Forecasting in Patients with Spinal Cord Injuries with Quadriplegia. Part 1 —Through Path Analysis—***

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**Abstract:** This study was conducted with 31 patients with chronic spinal cord injury at a rehabilitation clinic. It clarified the relationship between ‘degrees of satisfaction with life’ and a ‘forecast future’ and determined factors influencing the degree of life satisfaction from physical, social and psychological perspectives using data on their psychological conditions and their forecasts of their lives one, three and five years after the interview. Results indicate that those who determined their own clinic departure time had significantly stronger satisfaction with their lives than those who did not. Moreover, those who forecast their own life for the subsequent three years as either positive or negative show a significantly strong tendency toward life satisfaction. In addition, there is no correlation and causal connection between physical/social factors and the degree of life satisfaction. Path analysis shows that the factors directly contributing to strong positive correlation with the degree of life satisfaction were (1) correlation of forecast and hopes for life three years later and (2) self-acknowledgement. The result regarding agreement between forecast and hopes supports “client-centered practice” as an ethos for occupational therapy; that ethos is playing a significant role in quality of life for the patient subjects.

**Key words:** life satisfaction, forecasting, spinal cord injury patients, QOL

*(Asian J Occup Ther 3: 1–13, 2004)*

### **Introduction**

Life expectancy for patients with spinal cord injuries has continued to lengthen, and, due to medical progress and management technologies, is approaching normal life expectancy (Whiteneck, 1992). Concomitant with this trend, there are increasing reports of drug abuse, depression, and

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Received: December 1, 2002, Accepted: February 15, 2004  
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suicide of chronic spinal cord injury patients in the United States (Geisler, 1983; Macleod, 1988; DeVivo, 1991). It is estimated that negative, perhaps pessimistic, forecasts affect the degree of life satisfaction (Spencer, 1997; Moriya, 1994) in addition to other psychological, physical and social factors (Pentland, 1998; Yerxa, 1990; Kawamoto, 1998). Moriya, after studying those who attempted suicide, concluded that those patients who cannot find meaning in their present life because of negative prospects tend to commit suicide. However, no research has addressed the relationship between patients' satisfaction with present life and their future prospects.

This study examines chronic spinal cord injury patients to clarify the relationship between their present degree of satisfaction with life and their future forecasts; it also determines interrelations between physical, social and psychological factors, which influence satisfaction.

## **Literature Review and Term Definitions on 'Forecasting'**

### *Literature review*

We searched related literature by computer and manually from available related and cited books. We used the words: *perspective*, *future*, *hope*, and *uncertainty* for computer search terms for a news and magazine article search database, a sociology literature information database, and MEDLINE (1991–2000).

We can now find research that examines future perspectives in the field of clinical psychology from the late 1950s to the early 1970s. Wallace (1958) defined future time perspective (FTP) as an opposing concept of past time perspective (PTP); FTP refers to chronological adjustment and the order of events that may happen to each individual, thus including foresights and coherences.

These studies were developed from the Logotherapy School. One of the therapies established by Frankl. Logotherapy (Frankl, 1966) has been utilized to encourage patients to overcome aimlessness and promote the process of finding meaning in life (Kastenbaum, 1961;

Heimberg, 1963; Black, 1973). The number of new studies addressing such forecasting has decreased gradually, year by year.

However, during the 1970s, when the Human Rights Movement engendered ethics of medicine, behavioral science research was born to explore the meaning of life when living with illness and the influence of patients' perceptions of life-meaning on their own health. It had been thought impossible to measure the state of recognition of self-consciousness objectively by identification and transformation, but in the second half of the 1980s, some reports were based on the notion that they could explore a new stream of cognitive behavioral study from patients' experiences. We obtained some studies that examined relationships with FTP in these frameworks (Yarcheski, 1988). Herein, FTP refers to uncertainty of self-recognition—uncertainty occurring when one needs to make a decision, i.e., one either cannot find the meaning of the event or cannot accurately forecast the future; therefore, FTP focuses on the span of what one has forecast while also addressing the importance of the forecast in proportion to the span.

More recently, it has been acknowledged that consciousness of the future plays a significant role in one's present state of mind (Spencer, 1997; Johnson, 1997). This argument is supported by those in the health care field and also by philosophers, theorists and social scientists, yet the study of FTP has just started to grow; few theses in this area have been published.

### *Definitions of terms*

#### 1) Future Time Perspective

FTP, as defined in past studies, refers to "chronological prediction and order of events that may happen to each individual" and thus applies to individuals when they may have events already set up such as retirement and death. It deals with long-term predictions; it is therefore difficult to take them into consideration for the study of their relationship with the present state of mind.

In order to find the relationship of FTP with the present state of mind, as we do in this study, we conclude that we should address the immediate future and the forecasting of the "environment:

**Table 1.** Characters of the samples (N=31)

	<u>Mean error rate</u>	<u>Standard deviation</u>	<u>Min-Max</u>	
Age (year)	32.84	9.78	18–54	
Months of infection	58.29	30.19	20–145	
Months residence at the clinic	24.42	15.56	2–56	
ADL (FIM)	84.35	19.07	53–115	
	<u>Well</u>	<u>Bad</u>		
Acceptance by family	28	3		
Employment relations	7	24		
	<u>Compensation of Absence from Work</u>	<u>Pension</u>	<u>No Pension</u>	
Financial status	7	12	12	
	<u>Accident</u>	<u>Work</u>	<u>Recreation</u>	<u>Other</u>
Cause of infection	14	8	5	4
	<u>Range</u>	<u>Max level</u>	<u>Complete paralysis</u>	<u>Incomplete paralysis</u>
Functional level (Zancolli)	C4-III A, II B	II B1: 8	30	1

people, place and society” surrounding the individuals; also, the forecast should include both hope and prediction.

## 2) Degree of Life Satisfaction

Life Satisfaction is defined as an evaluation of how much one is satisfied with one’s present condition according to certain criteria such as one’s hopes and goals. This has been used as an index of subjective feeling of happiness in the fields of sociology and psychology.

In this paper, the LSI (Life Satisfaction Index), developed by Neugarten *et al.* (1961) is used to evaluate correlations between scores from questions inquiring about ‘present life satisfaction’ and ‘total scores of LSI’; they have a positive correlation ( $r=.956$ ,  $P<.000$ ), so the LSI total is regarded as a legitimate proxy for present life satisfaction and is used here.

## Methods

### Samples

Samples used in this study include 31 chronic external spinal cord injury patients (28 men and 3 women) with low probabilities of recovering physical functions in the future and who are

hospitalized at an I Rehab Clinic. Their ages ranged from 18 to 58 yrs. (mean  $32.84 \pm 9.78$  yrs.). All were informed about the purpose and content of this study and agreed to participate in it. The author went to the clinic as an examiner for five days from August 10–14, 1998. Sample characteristics are shown in Table 1.

### Research methods

We used interview and questionnaire survey methods for this research. Details are as follows.

#### (1) Semi-structured interview on FTP.

The author made the following questionnaires of FTP based on the concept of future hopes developed by Spencer (1997); each question was asked individually.

##### 1) Hopes for the Future

Questions addressed what, where and with whom one would be doing activities in one, three and five years subsequent to the interview. For the third year, we hypothesized that the patient would be discharged from the clinic (given the three-year limit to which one can remain in the rehabilitation clinic). Situations where one was able to conceive of and talk about future hopes were labeled as *possible to express one’s future hope*; situations

where patients were unable to imagine or even think of their own future were labeled as *impossible to express one's future hope*.

#### 2) Prediction of the Future

These questions addressed patients' ability to predict what, where, and with whom one would be doing activities one, three and five years hence; for the third year, we hypothesized that patients would already be discharged from the clinic (given the three-year limit for stays in the rehab clinic). If one is able to conceive of the future, the case is labeled as *possible to predict the future*; if one cannot conceive or even want to think of the future, the case is labeled as *impossible to predict the future*.

#### 3) Forecasting the Time of Discharge from the Clinic

These questions concern whether the time for discharge from the clinic is determined and whether the decision-maker is the patient or another person.

(2) Questionnaire Survey Regarding the State of Mind including Life Satisfaction Index: The following four types of questions were created based on the framework of Psychological Construct by Christiansen & Baum (1991) in a self-marked form.

##### (i) Degree of Life Satisfaction

Life Satisfaction Index (LSI) by Neugarten (Morimoto, 1991: translation into Japanese). It consists of 20 questions such as "Are you satisfied with the life that you have had thus far?" Answers were chosen from *Yes: Point 1, Neither or I don't think so: Point 0*. The score range is 0–20.

##### (ii) Degree of Depression

The Self-rating Depression Scale (SDS) by Zung (1965) is used here. It consists of 20 statements such as "I cannot sleep well at night." One then chooses from four answers: *No, P 1; Sometimes, P 2; Often, P 3; and Always, P 4*.

The score range is 20–80. The raw score—score total raised to the 1.25th power is called the *Zung Index*; if the index is 50 and more, one is considered to have symptoms of depression.

##### (iii) Self-esteem

The self-esteem scale developed by Rosenberg (1965) is used here. It consists of 10 questions such as "I wish I could be proud of

myself a little more." One can choose either: *I think so very often, P 5; I often think so, P 4; Neither, P 3; I don't think so very much, P 2; or, I don't think so at all, P 1*. The score range is 10–50. Self-esteem is indicated by responding with "I like—" or "I don't like—" "It is good/bad." toward a concept of oneself such as "I am—" Thus, it indicates values to which one would consider him/herself attached.

##### (iv) Internal/External Locus of Control (LOC)

LOC by Kamahara (1982) is a revision of Rotter's Internal/External Scale. It consists of 18 questions including, "Do you think you make decisions concerning your own life on your own?" One chooses from four answers: *I think so, P 4; I think so a little, P 3; I don't think so very much, P 2; and I don't think so at all, P 1*. The score range is 18–72. Higher scores indicate stronger feelings of an external LOC. Therefore, one would believe that the cause of a problem pertains to oneself; one would then try hard to achieve goals to improve matters. On the other hand, the lower the LOC, the weaker the external locus of control; one would feel dependent on fate or luck for their life in dealing with a problem.

(3) An individual semi-structured interview on occupations, the COPM (Canadian Occupational Performance Measure) developed by Law *et al.* (1994), was used to determine problems and interests in occupational performance. We asked respondents to list activities that they 'want to', 'need to', and 'are expected to' do; then we prioritized them and took the top five of these.

##### (4) Semi-structured Interview on Life Meaning

Through interviews, we asked for detailed content and reasons for individuals' perceived meaning of life. We excluded items for which they felt joy, but didn't attach life-meaning to.

#### *Analysis of results*

After having calculated descriptive statistic values, we analyzed relationships of data. Spearman's correlation was used for quantitative variables (age, FIM, time to leave the clinic, the number of occupational needs, the number of life-meanings, life satisfaction index, degree of depression, self-esteem level, and LOC). Mann-

**Table 2.** Hopes and predictions of the time to leave the clinic and the future for 1, 3 and 5 years later

NO.	Time to leave the clinic on their own	1 year forecast			3 year forecast			5 year forecast															
		With whom		Doing what	With whom		Doing what	With whom		Doing what													
		Predict	Hope	Where	Predict	Hope	Where	Predict	Hope	Where													
1	Decided*	○	P	unspec.	H	Pc	J	ADL	○	○	J	H	Parent	H	Parent	H	Parent	H	Parent	J	J	NCL	
2	Undecided	×	S	×	×	×	×	×	×	×	×	×	×	S	S	S	S	S	S	S	×	×	×
3	Undecided	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×
4	Decided	○	unspec.	unspec.	Pc	Pc	ADL	ADL	○	○	ADL	ADL	ADL	Parent	Parent	Parent	Parent	Parent	Parent	Parent	Parent	Parent	PinS
5	Undecided	○	unspec.	unspec.	H	H	L	L	○	○	ADL	ADL	ADL	Parent	Parent	Parent	Parent	Parent	Parent	Parent	Parent	Parent	PinS
6	Decided*	○	Parent	Parent	H	H	L	L	○	○	L	L	L	Parent	Parent	Parent	Parent	Parent	Parent	Parent	Parent	Parent	PinS
7	Decided*	×	S	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×
8	Decided	○	unspec.	unspec.	V	V	J	J	○	○	J	J	J	○	○	○	○	○	○	○	○	○	○
9	Undecided	○	unspec.	unspec.	W	Pc	O	ADL	○	○	L	L	L	○	○	○	○	○	○	○	○	○	○
10	Decided*	○	Parent	Parent	H	H	LfH	LfH	○	○	L	L	L	○	○	○	○	○	○	○	○	○	○
11	Decided*	○	Parent	Parent	H	H	L	L	○	○	L	L	L	○	○	○	○	○	○	○	○	○	○
12	Undecided	×	unspec.	×	Ncf	×	L	L	○	○	×	×	×	×	×	×	×	×	×	×	×	×	×
13	Decided*	○	A	unspec.	L	L	O	O	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
14	Undecided	○	unspec.	unspec.	Pc	Pc	ADL	ADL	○	○	ADL	ADL	ADL	○	○	○	○	○	○	○	○	○	○
15	Undecided	○	Parent	Parent	H	H	J	LfH	○	○	J	J	J	○	○	○	○	○	○	○	○	○	○
16	Decided*	○	Parent	Parent	H	H	J	PinS	○	○	J	J	J	○	○	○	○	○	○	○	○	○	○
17	Decided*	○	A	unspec.	L	L	HSE	J	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
18	Undecided	○	unspec.	unspec.	Pc	Pc	ADL	ADL	○	○	ADL	ADL	ADL	○	○	○	○	○	○	○	○	○	○
19	Decided*	○	S	unspec.	H	H	J	J	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
20	Decided	○	unspec.	unspec.	Ncf	Ncf	ADL	ADL	○	○	ADL	ADL	ADL	○	○	○	○	○	○	○	○	○	○
21	Undecided	○	unspec.	unspec.	Pc	Pc	ADL	O	○	○	ADL	ADL	ADL	○	○	○	○	○	○	○	○	○	○
22	Decided*	○	A	unspec.	L	L	L	L	○	○	L	L	L	○	○	○	○	○	○	○	○	○	○
23	Decided*	○	Parent	Parent	H	H	L	L	○	○	L	L	L	○	○	○	○	○	○	○	○	○	○
24	Undecided	○	S	unspec.	H	H	ADL	ADL	○	○	ADL	ADL	ADL	○	○	○	○	○	○	○	○	○	○
25	Decided*	○	Parent	Parent	H	H	J	J	○	○	J	J	J	○	○	○	○	○	○	○	○	○	○
26	Decided	○	unspec.	unspec.	Pc	Pc	ADL	ADL	○	○	ADL	ADL	ADL	○	○	○	○	○	○	○	○	○	○
27	Undecided	○	Parent	Parent	H	H	LfH	O	○	○	L	L	L	○	○	○	○	○	○	○	○	○	○
28	Decided*	○	Parent	Parent	H	H	L	L	○	○	L	L	L	○	○	○	○	○	○	○	○	○	○
29	Decided*	○	Parent	Parent	H	H	J	J	○	○	J	J	J	○	○	○	○	○	○	○	○	○	○
30	Undecided	○	unspec.	unspec.	Pc	Pc	ADL	ADL	○	○	ADL	ADL	ADL	○	○	○	○	○	○	○	○	○	○
31	Undecided	○	Parent	Parent	H	H	J	J	○	○	J	J	J	○	○	○	○	○	○	○	○	○	○

Correct or incorrect forecasting	With Whom			Where			Doing what												
	Unable to predict	×	○	Unable to predict	×	○	Unable to predict	×	○										
able to predict	Parents Alone	Partner	Spouse	Unspec.	Parent	A	Home	Present clinic	Nursing care facility	Ncf	ADL training	Leisure	Looking for home	Occupational training	Participation in society	HS Equivalence	Job	Study Abroad	SA
unable to predict	Parents Alone	Partner	Spouse	Unspec.	Parent	A	Home	Present clinic	Nursing care facility	Ncf	ADL training	Leisure	Looking for home	Occupational training	Participation in society	HS Equivalence	Job	Study Abroad	SA

**Table 3.** The number of occupational needs, their priorities and their fields

No.	First		Second		Third		Fourth		Fifth		
	Occupational need	Class	Occupational Need	Class	Occupational Need	Class	Occupational Need	Class	Occupational Need	Class	
1	5	Taking a bath	S/C	Driving	S/C	Relationship with people of the opposite sex	L/A	Individual housework	S/C	Twin basketball	L/A
2	5	Changing clothes	S/C	W/C movement	S/C	Restroom	S/C	Taking a bath	S/C	Telephone conversation with family	P/A
3	5	Restroom	S/C	Taking a bath	S/C	Job hunting	P/A	Cooking with spices	S/C	Relationship with friends	L/A
4	5	Taking a bath	S/C	Driving	S/C	Restroom	S/C	Occupational PC training	P/A	Relationship with people of the opposite sex	L/A
5	5	Changing clothes	S/C	Restroom	S/C	Taking a bath	S/C	Driving	S/C	Pachinko	L/A
6	5	Getting a driving license	S/C	Occupational training	P/A	Repaying an obligation	P/A	Relationship with people of the opposite sex	L/A	Restroom	S/C
7	5	W/C operation	S/C	Improvement of physical condition	S/C	Expanding areas to move	L/A	Outdoor leisure	L/A	Socializing	L/A
8	2	Occupational training	P/A	Driving	S/C		S/C		S/C		L/A
9	5	Changing sheets	S/C	Incontinence control	S/C	Occupational training	P/A	Housework in general	S/C	Socializing	L/A
10	5	Getting a driving license	S/C	Occupational training	P/A	Evening entertainment	L/A	Conversational skills	L/A	Relationship with people of the opposite sex	L/A
11	5	Participation in an organization	P/A	Creative activity	L/A	Making connections with society	L/A	Going out	L/A	Contacting other people	L/A
12	5	Leisure	L/A	Improvement of physical condition	S/C	Care of bed-sore	S/C	Changing clothes	S/C	W/C movement	S/C
13	2	Relationship with staff	L/A	Relationship with people of the opposite sex	L/A		L/A		L/A	Occupational training	P/A
14	5	Improvement of physical condition	S/C	Improvement of academic competence	P/A	Cooking	S/C	TV games	L/A		
15	4	W/C movement	S/C	Restroom	S/C	Taking a bath	S/C	W/C operation	S/C		
16	2	Socializing	L/A	Preparation for work	P/A		P/A				
17	1	Relationship with parents	P/A								
18	5	Restroom	S/C	Taking a bath	S/C	W/C movement	S/C	Lower-body-controlling band control	S/C	Changing a urine bag	S/C
19	4	Rules of the clinic	L/A	Preparation for work	P/A	Expanding hobbies	L/A	Free movement	L/A		
20	2	Restroom	S/C	Taking a bath	S/C		S/C				
21	2	Driving	S/C	Occupational training	P/A		P/A				
22	1	Relationship with parents	P/A								
23	4	W/C movement	S/C	Restroom	S/C	Taking a bath	S/C	Maintaining physical condition	S/C		
24	1	W/C operation	S/C								
25	3	Driving	S/C	Preparation for work	P/A	ADL independence	S/C	Taking a bath	S/C	W/C control	S/C
26	5	W/C movement	S/C	Restroom	S/C	Changing clothes	S/C	Writing letters	L/A		
27	4	W/C movement	S/C	Getting a high-level architect license	P/A		P/A				
28	1	Internet	L/A			Improvement of physical condition	S/C				
29	0	Nothing	N			Preparation to work	P/A	Job hunting	P/A	Restroom	S/C
30	4	Taking a bath	S/C	W/C movement	S/C		S/C	Intensive training	S/C		
31	5	Changing clothes	S/C	W/C movement	S/C		S/C				

\* Classifications of areas of occupational performance; N: Nothing at all, S/C: Self-care, P/A: Productive Activity, L/A: Leisure Activity


**Table 4.** Presence and absence of meanings of life and the contents

No.	Value	Areas of meanings of life	Contents of meanings of life	Reasons
1	2	Leisure	Twin basketball	Fun. I am originally sports person. I like it.
2	0	Leisure	Driving	To expand the area where I can move. I can go to wherever I like.
3	0		Maybe nothing	
4	1	Leisure	I don't feel it.	I can no longer do my former hobby.
5	1		Computer games	I can be excited with it forgetting myself.
6	2	Leisure	Nothing	There are fun things but I can't call them the meaning of life.
7	3	Leisure	Relationship with friends	For recreation, supporting relationship
		Leisure	Relationship with other residents	Motivation to be positive.
		Leisure	SCL Flight Project	I can give others joy and hope.
		Leisure	Demonstration Project of JOIBAN	I can give others joy and hope.
		Leisure	Writing music lyrics	It's my only way to let others know of me.
8	0		Nothing special	
9	1	Self-care	Training	I am going for my goal.
10	1	Leisure	Trip planned by myself	Originally, I liked to make a trip.
11	2	Production/Role	Existence of mother	I cannot die before my mother, so I am making efforts.
		Leisure	Conveying my own life	I want to tell others that there are fun things about being alive.
12	1	Self-care	Improving physical condition	I want to change from 80% nursing care to 80% independence.
13	2	Leisure	Existence of friends	They can make me feel that I can make efforts.
		Leisure	Existence of a person that I love	They can make me feel that I can make efforts.
14	1	Self-care	Efforts to meet a goal to improve physical condition	I need to be cautious about my mental condition.
15	1	Production/Role	Living with parents in my hometown	To apologize to them for doing things I wanted to do.
16	1	Production/Role	Getting jobs	I want to get paid for what I do.
17	2	Leisure	Meet new people	Fun. There are various kinds of people.
		Leisure	Socializing with people	I can learn a lot from them.
18	0		Nothing	
19	4	Self-care	ADL independence	I don't want to have assistance from my daughter.
		Leisure	Reading	I can collect information for my job eventually.
		Leisure	W/C Mapping	It's useful.
		Production/Role	Stock investment	I can feel that I am working myself.
20	2	Self-care	Preparation for the future	I can have positive forecasting now that I can do 1/4 of the things I want to do.
		Leisure	Existence of friends	Support. They can make me forget that I am disabled.
21	1	Selfcare	Independent life	It's important to live without getting support from others.
22	2	Leisure	Existence of friends	We can solve problems together. I can talk with them about anything.
		Production/Role	Plant to be independent	It's important to create a life of my own.
23	1	Self-care	Independent use of restroom	First I thought I could not be independent. But, once I achieve it, I can feel satisfaction.
24	1	Production/Role	Growth of children	I want to keep a close watch on their growth.
25	1	Leisure	Existence of friends	Fun. I can have consultation with them.
26	0		Searching	
27	2	Production/Role	Jobs	It's necessary to live.
		Self-care	Broadening possible activities	Do things for myself on my own.
28	0		No	Movies are fun. Computers and delicious food are also fun.
29	0		No	Never thought of that before. I can have fun chat with my friends, though.
30	0		Nothing I can think of as meaning of life	Before infection, I was an instructor for a swimming school. It was my meaning of life.
31	1	Self-care	Training	I can get at the moment, I feel I can increase the things I become able to do.

Whitney's non-parametric examination and Goodman-Kruskal's Gamma were used to examine qualitative variables (presence/absence of an employment relationship, presence/absence of a self-determined time to leave the clinic, predictions of life in one, three and five years, along with the degree of correlation of predictions

and hopes, contents of occupational needs, and contents of life-meanings); their level of significance was less than 5%. Also, in order to create a path model with the LSI as a dependent variable, factors considered to influence LSI were used for factor analysis. Such factors included the following 25 parts of data: age; purpose for stay at

**Table 5.** Order of Positive and Negative Views for Forecasting the Future

Order	With whom	Where	Doing what
Negative	Unable to predict	Unable to predict	Unable to predict
	Not specific	Nursing care facility	Nursing care life
	Parents	Present clinic	ADL training
	Alone	Home	Leisure
	Partner	Work rehabilitation	Looking for home
	Spouse	Vocational aid center	Occupational training
		Living alone	Participation in the society
		Living abroad	Job
Positive			University entrance exam / Studying abroad

the clinic; financial security; presence/absence of an employment relationship; functionality of the spinal cord (Zancolli, 1968), ADL (Hamilton, 1987; Chino, 1991); forecasting (prediction and presence/absence of a self-determined time to leave the clinic, prediction of life one and three years hence, degree of correspondence between hope and prediction three years later); occupational needs (content and number); meanings of life (content and number); state of mind (LSI, depression rate, self-esteem rate, and LOC). The principle-factor method, regression analysis, and Waldo Statistic Value were used for path analysis. Statistical processing was performed with SPSS (2001). Statistical Package for the Social Sciences (Version 10.0), and AMOS (2001) (Version 4.0) [Computer software]. Chicago: Author. The level of significance was less than 5%.

## Results

Results for the 'degree of life satisfaction and psychological aspects' for all subjects were LSI Mean 7.06 (SD  $\pm$  4.39, range 0–15) and Zung Index Mean 55.65 (SD  $\pm$  8.44, range 38.75–72.5); 22 patient subjects showed symptoms of depression (71%) and 9 did not (29%). Regarding self-esteem, the Mean score was 31.61 (SD  $\pm$  4.22, range 23–44) and the LOC was Mean 48.35 (SD  $\pm$  19.07, range 33–64). Results of the 'evaluation of future forecasting' are shown in Table 2; Table 3 shows 'occupational needs' and Table 4 shows 'meaning of life'.

### *Ordinality of positivity and negativity of future forecasting*

Table 5 shows a hypothetical table demonstrating that predictions are more negative than hopes after extracting all data: 'we can predict and hope but they don't match' and 'we can hope but cannot predict'. There are two cases out of 279 for which predictions are higher than hopes. After reviewing the interviews, we found that they were doing things that they don't want to do under conditions that they have to do, answering 'I have to work though I don't want to' or 'Though I don't know what to do, I cannot help having nursing care'. We checked frequency of occurrence for each section with Goodman-Kruskal's Gamma comparison; all predictions and hopes showed positive correlation ( $p < .05$ ).

### *Relationships with future forecasting, degree of life satisfaction, and each aspect here we discuss influential factors*

Factors influencing the degree of life satisfaction (Table 6): With the Life Satisfaction Index, positive correlation was found with self-esteem and LOC; negative correlation was found with the depression rating. To a significant degree, it was found that those with higher LSI and LOC and lower depression index tend to decide the time to leave the clinic on their own. Moreover, those with higher LSI and a lower depression index can significantly forecast life even three years later. Positive correlation was also found between meaning of life and self-esteem index/LOC. Thus, those who have



**Table 6.** Factors with correlations

	Correlations, verification value	Statistical method
Life satisfaction index vs.		
Psychological aspect		
LOC	0.586**	Spearman rank correlation (rs)
Self-esteem	0.426*	Spearman rank correlation (rs)
Depression control	0.600**	Spearman rank correlation (rs)
Presence / Absence of depression symptom	39.500**	Mann-Whitney verification (U)
Future forecasting		
Presence / Absence of self-decision making on the time to leave the clinic	40.000**	Mann-Whitney verification (U)
Presence / Absence of forecasting for the next 3 years	36.5000*	Mann-Whitney verification (U)
Number of meaning of life vs.		
LOC	0.715**	Spearman rank correlation (rs)
Self-esteem	0.529**	Spearman rank correlation (rs)
Presence / Absence of meaning of life including leisure fields vs.		
Depression control	1.000**	Mann-Whitney verification (U)
Self-esteem	7.500*	Mann-Whitney verification (U)

\*\* Significance 1%. \* Significance 5%

productive tasks and leisure tasks tend to display a higher self-esteem rate and a lower depression rate than those who are limited to self-care as their meaning of life.

### *Causal relationship of LSI as a dependent variable with all factors (25) and creation of a path model*

We created a path model with the following path analysis.

#### 1) Factor Analysis and Labeling of Factors

In order to determine potential variables for the 25 factors on: general characteristics (year of injury, functioning level, self-esteem level, FIM, financial state, family acceptance), state of mind (LSI, Depression Index, Self-esteem Index, Internal/External LOC), meaning of life, occupations of interest, and forecasting, we carried out exploratory factor analysis. Using the principle factor method as an extraction method, six factors (contribution rate 73.1%) were extracted. We labeled each factor as follows: factor 1, self-image in the near future; factor 2,

present self-consciousness; factor 3, gap between hope and prediction in forecasting; factor 4, decision-maker of the clinic discharge time; factor 5, physical ability; and factor 6, employment.

#### 2) Reliability Analysis of Each Factor, Narrowing Down of the Section within a Factor and its Correlations

Next, we carried out reliability analysis for sections given to each factor (observed variables). After breaking down the factors to maximize reliability of each factor, we analyzed respective correlations between six factors and life satisfaction index (Table 7).

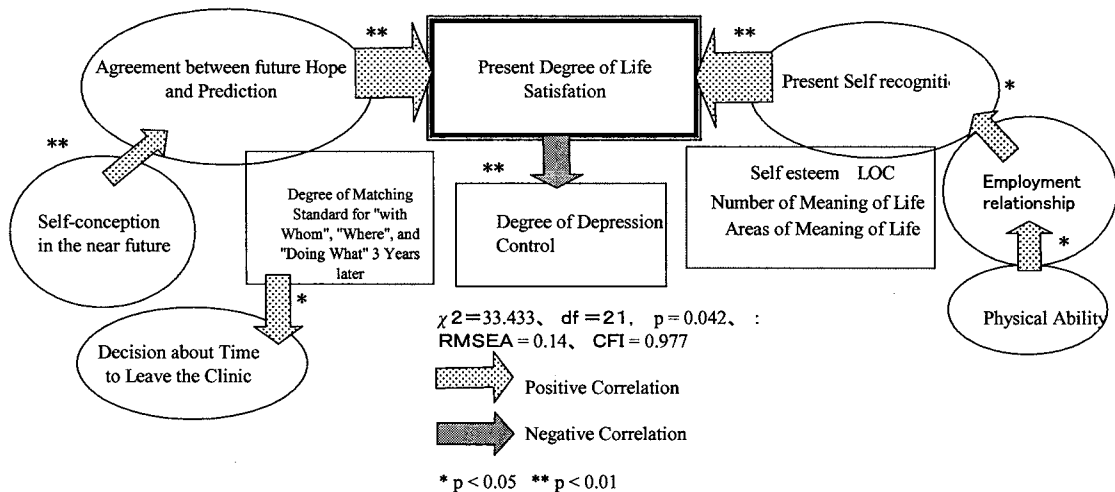
#### 3) Regression Analysis (Stepwise Method) for Creation of the Path Model

Next, we created a path model for LSI based on regression analysis results (Fig. 1). In all factors, the C.R. variance was over 1.96. All path was the level of significance, less than 5%. The residual variance matrix was -2.286 to 2.816; no large residual was found with fine data matching ( $\chi^2=33.433$ ,  $df=21$ ,  $p=.042$ ; RMSEA=0.140; CF I=.977).

**Table 7.** Correlations between Credibility Factor / Life Satisfaction and Each Factor

	LSI	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
Credibility factor ( $\alpha$ )							
		0.8738	0.6465	0.8225	0.8603	0.2501	0.6745
Spearman rank correlation (rs)							
Life Satisfaction Index (LSI)	1						
Factor 1: Self-conception in the near future	0.416*	1					
Factor 2: Present self-recognition	0.575**	0.354	1				
Factor 3: Agreement between future hope and prediction	0.492**	0.550**	0.008	1			
Factor 4: Decision about time to leave the clinic	0.588**	0.683**	0.503**	0.297	1		
Factor 5: Physical ability	-0.106	0.137	0.231	-0.259	0.049	1	
Factor 6: Employment relationship	0.067	0.259	0.266	-0.101	0.361	0.269	1

\*\*Significance 1%. \*Significance 5%.



**Fig. 1.** A path model for LSI based on regression analysis results

**Considerations**

*The relationship between LOC for the future and life satisfaction*

Those who had decided the ‘time to leave clinic’ for themselves had a significantly higher degree of life satisfaction than those who had not. In addition, with regard to the relationship between life satisfaction and matched/mismatched

groups of predictions and hopes, the group with samples with matching of forecasting on ‘what, where, and with whom one would be doing activities in three years’ showed a significantly higher degree of life satisfaction ( $p < .01$ ). Because we hypothesized that patients would leave the clinic after three years, we concluded that being able to forecast life after leaving the clinic was the factor that increased the degree of life satisfaction.

Moreover, whether or not patients themselves can forecast their lives in the near future and predict a hopeful future are keys to change in the life satisfaction index. This is the same conclusion that Saka *et al.* (1998) suggested: “being able to control one’s own life increases life satisfaction.”

From results shown above, ‘three years’ was the time that influenced present life satisfaction most. The average number of months of residence at the clinic for these patients was 24.4; therefore, ‘three years’ for most of these patients is interpreted as about two years after leaving the clinic. At this stage, patients face the reality of having to consider their future direction of progress; therefore, influence on life satisfaction becomes very high.

Though Post *et al.* (1998) published a multi-dimensional path model, it is significant in this paper that we take the ‘future forecasting’ aspect into consideration for the path model; this aspect is a new development in this area of study. The most influential factor in forecasting was the ‘degree of matching of hope and prediction’. This is an interesting result for Occupational Therapy: it clearly shows that an inherited philosophy from the birth of OT—“client-centered practice” (Meyer, 1922/1977)—plays a significant role in QOL for the patients. This concept should be borne in mind not only for those in OT, but also for all individuals in medicine, welfare and health care since the Human Rights Movement has revealed the significance of ‘medical care ethics’; the possibility of its application must be high.

### *Elements that shape the “degree of life satisfaction”*

Factors influencing the degree of life satisfaction include the ‘factor of gap between future prediction and hope in three years’ on what, where and with whom (24.0%), and ‘present self-recognition factor’ such as “self-esteem,” “LOC” and “meaning of life” (26.0%). It could be interpreted that the ‘factor of gap between future prediction and hope’ either directly influences life satisfaction or does so indirectly through ‘determinant factor of when to leave the clinic’. Also, the ‘degree of depression’ is influenced only negatively by life satisfaction. With regard to the

relationship with the depression rating, multiple reports have been presented on acceptance process of disabilities, depression when having injuries, chronic pain, personality, long-term medication with narcotics or tranquilizers, and ADL independence status (Guttmann, 1945; Thom, 1946; Fink, 1967; Elliott, 1991, 1996; Honda, 1992; Nagumo, 1994, 1999; Lo, 1993). Still, factors other than life satisfaction were found in these reports. This study did not show the relationship with physical aspects and social aspects such as employment and acceptance by family members. Though the ‘physical ability’ factor influences the ‘employment-relationship’ factor and the ‘employment-relationship’ factor influences the ‘present self-consciousness’ factor in turn, they have only indirect influences on the degree of life satisfaction. As a result, this study found no relationship between physical aspects and life satisfaction, as with the report by Post *et al.* (1998). This may be due to the fact that the patient subjects are in the chronic stage where there is little chance of recovering full physical capability; therefore, they pay more attention to how to live life. Though Yerxa (1990) and Kawamoto *et al.* (1998) reported that presence or absence of employment and ADL independence level influences the degree of life satisfaction, this study showed no relation between social aspects and life satisfaction. One explanation is that all subjects in this study were hospitalized and unemployed. In addition, it is difficult to explain the relationship only by presence and absence of an employment relationship: ‘type of employment’ and ‘meaning of jobs for each individual’ must have some influence on the degree of life satisfaction in past research.

Results of this study support past research that argues for the importance of patients’ forecasting. The fact that the ability to forecast has more influence than present physical and social conditions introduces a new perspective into the practice of rehabilitation.

As the number of subjects was only 31 this time, there is some restriction on the reading of the outcome of the multivariate analysis. Further research must address the authenticity of ‘forecasting’ that subjects have; studies should

also provide chronological follow-up research and suggest supportive measures to increase the degree of life satisfaction.

**Acknowledgement:** I would like to extend my gratitude to the patients in the Ito National handicapped with a high degree of disability Center and its Occupational Therapist, Mr. Koji Iwai, for their cooperation in collecting data.

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## ***Transition Related Dilemmas of Persons with Developmental Disabilities***

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**Abstract:** This study describes school to post-school transition problems, factors, activities and professionals involved in transition. Parents (n=86) of children with developmental disabilities, aged 14 and older, answered a questionnaire addressing study objectives. Parents reported work, psychological, coping and environmental problems related to transition. Factors perceived to facilitate smooth transition include coordination among service providers, early planning, presence of support systems and training in and exposure to post-school environments/activities. Lack of adolescent and adult programs, absence of planning and lack of knowledge about transition were perceived to hinder smooth transition. Activities listed for transitioning include planning, contact with agencies, professionals and potential employers, and work training. Teachers, doctors and occupational therapists were reported to be involved in the process. Results suggest a practice area addressing adolescent and adult needs. Further studies are needed to explore the efficacy of transition programs for this population.

**Key words:** school to work transition, developmental disabilities, transition planning and activities

(*Asian J Occup Ther* 3: 15–26, 2004)

### **Introduction**

Developmental disability (DD) represents a chronic, mild or severe group of disabilities resulting from mental or physical impairment or a combination of both. It also results in a substantial

functional limitation in three or more key areas of living (McDonnell, Wilcox & Hardman, 1991; Siporin, 1999). These areas include self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent learning, and economic sufficiency. Another working definition of DD conceptualized by Shapiro (as cited in Reyes, 1990) characterizes it as any disorder that critically affects a person's quality of life. This spectrum of disabilities include diagnoses such as mental retardation, autism, cerebral palsy, deaf-blind, learning disabilities, attention deficit disorder, and communication disorders (Clark & Kolstoe, 1995;

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Received: September 1, 2003, Accepted: February 25, 2004  
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McDonnell *et al.*, 1991; Shapiro as cited in Reyes, 1990).

As major areas of living are affected, persons with DD require ongoing support from their families, health, education, and social services throughout their lifespan (Siporin 1999; McDonnell *et al.*, 1991). Required services range from early intervention, special education, and vocational services that are modified as they grow older and their needs change. In the Philippines, most of the services are focused on early intervention and special education programs. Johnson (1995) asserted that there is a dearth of post-school programs for adolescents and adults with disabilities.

When it is time for persons with DD to leave the school environment, their families are in quandary as to what they will do. Some families expect them to be ready for work training, work per se or to function optimally in the community following completion of a school program. Options in the Philippines for this age group are limited and inadequate. When it is time for families to search for post-school placements, they discover that their children are inadequately prepared in terms of work skills and environment. Because of insufficient training, employment is difficult to find. Others resort to placing them back to school programs for further training or to simply keep them occupied. Many were also reported to stay home. As such, idleness and sometimes regression to infantile behaviors were also reportedly observed.

These experiences have heightened awareness among parents and professionals to address the need to prepare adolescents/adults with developmental disabilities for post-school environments. This preparation period is referred to as transition in this paper. This study documented transition related dilemmas and examined the factors that affect transition to a post-school environment. The investigator also identified activities and professionals involved in transition. It hoped to contribute to a knowledge base of the status of transition and adult programs for persons with developmental disabilities, and the extent of need for additional support services required in a developing country such as the

Philippines. This project aimed to provide impetus to create and develop transition programs by adult service providers and educational institutions. With transition programs in place for persons with disabilities, post-school adjustment and placement problems can be anticipated and minimized. This study can also be used to justify the design of individualized transition plans for adolescents with special needs.

Using a survey questionnaire, this study attempted to answer the following questions:

1. What problems are commonly observed among those with transition and without transition?
2. What factors facilitate/hinder smooth transition to post school environments?
3. What activities are used to transition persons with developmental disabilities from school to post-school environments?
4. Who are the professionals involved in the transition process?

The words “problem” and “dilemma” are used interchangeably throughout the paper. They refer to obstacles experienced and observed when a person with DD is prepared for post-school environments. Problem categories were operationally defined as:

1. Psychological—emotional responses to a variety of situations such as confusion, depression, withdrawal, and anxiety.
2. Coping—difficulties in adjusting or modifying behavior in response to environmental demands such as accommodating change, learning new routines, and interacting with new persons.
3. Behavioral—engagement in non-productive or maladaptive responses such as helplessness, increase in self-stimulatory activities, and preference for inactivity.
4. Work-related—difficulties related to carrying our tasks or responsibilities in school or non-school environments such as irregular attendance, learning work skills, managing money, and frequent tardiness.
5. Environmental—constraints or limitations found within context of family, community, and society such as lack of

support, lack of job options, lack of leisure opportunities, and no income to live independently.

## Literature Review

### *Transition Events*

Social scientists have theorized that in a person's lifespan, transitions are inevitable. Going to school, getting a job, moving to new place, and getting married are typical examples of transition events. Because it is a change that brings about "temporary disequilibrium" in a person's life, stress is experienced (Blair, 2000, p. 232). One of Levinson's stages of adulthood focused on the transitional period from adolescence to early adulthood (Rice, 1995). This period is characterized by stable and transition episodes. According to Levinson, it is during stable periods that adults develop values, belief systems, and life priorities. It is during times of transition that these may be modified in response to events. These episodes are closely related to Havighurst's developmental tasks of young adults, which include finding a job, spouse, and living away from parents (Rice, 1995; Schulz & Ewen, 1993). For the average person, transitions may be easily negotiated. A modification in routine, habit, and activity patterns is a typical response.

For persons with DD, one change is their transition from school to post-school environments that usually occurs between the ages of 14 to 22. A post-school environment may be a work place, new residence, an adult education program or living in the community. This is a period of preparation to enter these adult environments (Chandler, O'Brien, & Weinstein, 1996; Clark & Kolstoe, 1995; Horne & Morris, 1998; McDonnell *et al.*, 1991). They need to learn new response sets to deal with role change, new routines, responsibilities, occupations, skills, and habits. (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995; Jacobs, Mazonson, Pepicelli, Clague, & Leekoff, 1985).

A study by Hanley-Maxwell, Whitney-Thomas *et al.* (1995) described the visions of parents of children with disabilities. They portrayed their children working, living

independently, and having a network of friends outside of the family unit. Schuster, Graham and Moloney (2000) conducted a survey on post-high school expectations of students with disabilities and their parents. Students had higher expectations for themselves than their parents. They expected to work after high school congruent with their perception that it is a means to earn money, meet people, and feel responsible. Another study by Whitney-Thomas and Hanley-Maxwell (1996) revealed that parents experience a "greater discomfort and pessimism" of the future of their children with disabilities (p. 75). The time to confront a permanent departure from a school environment elicits tension and ambivalence (Blair, 2000) that affect family members.

The adjustment from school to a post school environment can be a difficult process.

It is well documented that a large number of persons with DD are unemployed or underemployed, have no or little access to leisure and community activities, are unable to make life decisions, and have very little independence (Clark & Kolstoe, 1995; McDonnell *et al.*, 1991). Many are not given opportunities to select their preferred placements. For those who work, Siporin (1999) reported that there was very little, if any, social interaction occurring between workers with DD and those without. She postulated that deficient preparation for a work environment was a reason for the lack of social interaction. Similarly, McInerney and McInerney (1994) found that adolescents with disabilities are deficient in social skills and work behaviors. A lack of essential skills for daily life in the community makes adolescents and adults with disabilities susceptible to maladjustment.

Hanley-Maxwell, Whitney-Thomas *et al.* (1995) asserted that the needs of this population require reliable and accessible services, wider range of residential options, support networks, and diverse experiences for successful transition.

### *Transition programs*

In the United States, federal regulations such as the Individuals with Disabilities Education Act (IDEA) and the School-to-Work Opportunities Act (STWOA) provided for transition services to



promote movement from school to post-school environments. Services included the following: post-secondary education, vocational training, integrated employment, adult services, independent living, and community participation (Clark & Kolstoe, 1995; Horne & Morris, 1998). In the Philippines, Republic Act 7277, also known as Magna Carta for Disabled Persons, does not have an explicit provision for transition services or programs.

Literature provided a variety of programs that address transition. Davidson and Fitzgerald (2001) described a client-centered transition-planning scheme aimed to facilitate a student's successful movement and integration from school to community environments. O'Reilly (2000) described a Transition Individual-Education Program of the Rochester Regional Transition Coordination Site. Getzel and Kregel (1996) proposed an employment connection program. McInerney and McInerney (1994) introduced a proactive occupational therapy program that addressed transition needs. Occupation-based programs (Ethridge, Dimmer, Harrison, & Davis, 1989; Giese, 2000; Kluver, Clark, & Hoffman, 1998) conducted in the community provided persons with DD opportunities to practice skills in natural settings. Schlien and Ray (1997) proposed the inclusion of therapeutic recreation services for a comprehensive transition program.

Occupational therapists are significant players in transition programs especially in the training of community living skills. Davidson and Fitzgerald (2001), Giese (2000), and Kluver *et al.* (1998) affirmed that our background on occupational performance provided occupational therapists the requisite to create community based instruction in instrumental activities of daily living (IADL), work task adaptations, communication, self-advocacy, consumer and legal issues, health management, housing options, personal assistance management, recreation, and transportation.

In the four programs described above and in other literature (Schuster, Graham, & Moloney, 2000), coordination and collaboration among parents, students with disabilities, teachers, adult service providers, and employers are emphasized. Hanley-Maxwell, Pogoloff, and Whitney-Thomas

(1998) emphasized the role of families during transition periods. Families of young adults with disabilities played multiple roles, and these interacted and overlapped with each other. Only one literature was found that cited the participation of pediatricians in the transition process (Johnson, 1995).

Early and effective transition services increase the likelihood that a person with DD will complete school equipped with enough skills to move on to post secondary education and meaningful work (Gloekler, 1998). Chandler *et al.* (1996), Kluver *et al.* (1998), and McInerney and McInerney (1996) cited case study evidences of persons with DD who were able to find employment and were successfully living in the community. The cases described skills practice in natural environments, job related activities, assessment of work related capacities, and exposure to various jobs. Much of the report of transition outcomes described in literature used case study designs. Longitudinal studies exploring effects of programs from transition planning are scarce, if not nil.

## Method

### *Participants*

The target population for this study included parents of adolescents and adults with developmental disabilities. For inclusion in the study, the only criterion considered was for a parent or guardian to have a son or daughter, aged 14 and older, diagnosed with any one of the following: Autism/Autism Spectrum Disorder (ASD), Down syndrome and Cerebral palsy, Attention Deficit Disorder, and Mental retardation.

A list of their parent-members with children within the specified age group was obtained from the Autism Society of the Philippines, Down Syndrome Association, and the Philippine Cerebral Palsy, Inc. Assistance from two (2) pediatricians and one (1) occupational therapist was also sought in the distribution of questionnaires to patients/clients who fit the criterion. Anticipating difficulty in accessing the target population, sampling was not done. The

study intended to include all parents/guardians who fit the inclusion criterion.

### *Instrument*

A mail questionnaire was designed containing questions that addressed the research questions. Content was gathered from literature (Chandler *et al.*, 1996; Getzel & Kregel, 1996; Hanley-Maxwell, Whitney-Thomas *et al.*, 1995; Johnson, 1995; McInerney & McInerney, 1994; O'Reilly, 2000) and from interviews of 13 parents seen at the Clinic for Therapy Services, a campus based clinic. A developmental pediatrician, an occupational therapist, and survey design expert reviewed the questionnaire. The University of the Philippines Manila-Filipino Language Center translated the questionnaire to the Filipino language.

Both the English and Filipino versions of the questionnaire were pilot tested to 5 parents of children with special needs aged 14 and older. Revisions were done based on feedback of the parents and experts. Categories/items in the questionnaire were also coded to facilitate encoding and data analysis.

Each question contained choices for the respondents to select what was applicable to them (Fig. 1). The first part asked for demographic characteristics of respondents and their adolescent/adult child with DD. Part II was for those respondents whose children were still enrolled in a school program. They responded to questions addressing current measures undertaken to prepare the person with DD from school to a post-school environment. Parents who reported having started transition were directed to proceed to questions in Part III that were relevant to them (questions four to eight). Part III was for those whose children were already in post-school environments. Questions pertained to the person's current activity level, residential status, transition activities undertaken, problems encountered (questions four and five), factors that facilitated or hindered the process (questions six and seven), and professionals (question eight) involved in transitioning.

Which of the following problems did your son/daughter have during or after the transition period? (cross out all that apply)

- \* Confusion
- \* Depression
- \* Withdrawal from friends and family
- \* Anxiety
- \* Difficulty accommodating change
- \* Difficulty learning new routine
- \* Helplessness
- \* Increase in self-stimulatory behaviors
- \* Preference for inactivity
- \* Inadequate skills learned in school
- \* Lack of recreational/leisure options
- \* Difficulty making decisions
- \* Aggressive behavior
- \* No or lack of paid job options
- \* Frequent tardiness in present program
- \* Others, please specify \_\_\_\_\_

**Fig. 1.** Sample question

### *Data collection and analysis*

A survey research method was employed for this study. Mailed questionnaires were coded with numbers for confidentiality to enable the investigator to track returns. Follow-up was conducted via telephone calls. Only those who had listed telephone numbers were contacted. Questionnaires were accompanied by a cover letter stating the purpose of the study, criteria for inclusion, and a statement of how their names were obtained. Postage paid business reply envelopes were included. A total of 344 questionnaires were sent out. Three hundred thirteen (313) were mailed. Thirty-one were distributed personally. Of those mailed, 19 were returned to sender with notations that addressees had moved with no forwarding addresses. Ninety-nine (99) were returned, yielding a response rate of 30%. Response rate was calculated by dividing the number of surveys returned and completed (n=99) by the population (n=325). Of the 99 returned questionnaires, thirteen (13) were found to be unusable. If questionnaires come with missing pages, or if the children did not fit inclusion

criterion, they were deemed unusable. The remaining 86 were used for data analysis.

Data analysis was done using descriptive statistics. Frequency counts and percentages and cross-tabulation were performed using the Statistical Package for the Social Sciences (SPSS) program.

## Results

Although 86 questionnaires were used, some questions were not applicable to all and not all respondents completed questions applicable to them; therefore, the number of responses varied for some questions. There were also questions that asked respondents to cross out all options that apply. In such cases, the sum may be more than the N for some of the results presented below.

### Demographics

Table 1 shows a demographic profile of the participants who were either parents or guardians of persons diagnosed with a developmental disability.

The mean age of the participants was 46 years. Clearly, over half of the group were middle-aged adults (76%) and female. Young adult participants (14%) were sibling-guardians of persons with DD. There were slightly more respondents from Manila than from the provinces. A majority (83%) received higher education. The group's (n=71) socio-economic profile reflected a middleclass to an upper middleclass background.

Mean age of adolescent/adult children with a developmental disability was 18 years. Their age range was 14–41 years old. Over half (67%) of the children were adolescents while the rest were young adults. Sixty-four (64) or 74 percent were males. A majority (48 or 56%) was diagnosed with Autism. Others were diagnosed with Down syndrome (20 or 23%), Cerebral palsy (12 or 14%), Attention deficit disorder (3 or 1%) and Mental retardation (3 or 1%).

Fifty-three (62%) of the children were still attending a school program. Thirty-three (38%) were out of a school environment. Of those in school, more than half (57%) were enrolled in special education programs. Programs attended

**Table 1.** Profile of parents/guardians

Profile Characteristics	Frequency	Percentage (%)
<b>Age (n=83)</b>		
20–30	2	2
31–40	10	12
41–50	45	54
51–60	18	22
61–70	8	10
<b>Sex (n=85)</b>		
Male	18	21
Female	67	79
<b>Residence (n=85)</b>		
Manila	45	53
Province	40	47
<b>Highest educ level (n=82)</b>		
Elementary	5	6
High school	9	11
College	46	56
Graduate school	22	27
<b>Annual family income (n=71)</b>		
39,999 & under	9	13
40,000–99, 999	19	27
100,000–499,999	31	44
500,000–over	12	17

were described as academic, vocational or both.

Among those in school (n=53), over half (62%) were perceived to extend their stay in a school environment up to adulthood. Of this group, less than half (22 or 42%) were reported to be transitioning to a post-school environment. The rest (31 or 58%) had not begun transition. Reasons for non-initiation of transition cited by a majority (77%) included no awareness of need for transition, no knowledge of available services and professionals to consult with.

Among those who had left school environments (n=33), 30 (91%) were home-based. One was working fulltime, another was enrolled in an adult education program, and one used to work in a computer shop but lost his job. Of this group, 25 (76%) reported no measures were adopted to

**Table 2.** Problems observed by parents/guardians

Problems	With Transition n <sup>a</sup> (%)	No transition n <sup>b</sup> (%)	Total n (%)
Psychological	22 (73)	14 (25)	36 (42)
Coping	17 (57)	21 (38)	38 (44)
Behavioral	15 (50)	19 (34)	34 (40)
Work	23 (77)	14 (25)	37 (43)
Environmental	9 (30)	24 (43)	33 (38)

<sup>a</sup>=30; <sup>b</sup>=56. Percentages add up to more than 100 due to multiple responses.

**Table 3.** Perceived factors affecting transition (n=86)

Facilitating Factors	n	%
Coordination among service providers	76	88
Early planning	53	62
Presence of support systems	42	49
Prior training/exposure to different environments/activities	38	44
<b>Barriers</b>		
Lack of services/programs	79	92
No planning	74	86
No knowledge of transition	42	49
Lack of support	24	28
Lack of coordination	21	24
Others (financial, stigma)	13	15

prepare their children for a post-school environment. Only 8 (24%) reported conducting activities related to transition.

Altogether, 30 (35%) underwent transition related activities and 56 (65%) did not undergo any transition.

### *Problems observed*

Problems reported observed during and after transition were classified into 5: psychological, coping, behavioral, work related and environmental (Table 2). Parents reported a mix of problems.

Table 2 shows that respondents of those with and without transition reported almost equally the same types of problems. A majority of the respondents, whose adolescent children underwent transition, observed more work, psychological,

and coping related problems. In contrast, more environmental problems were observed among those without transition.

### *Factors affecting transition*

Factors perceived to facilitate a smooth transition from school to a post-school environment included the following: early planning, coordination among service providers, presence of support systems (family and friends), and prior training in different environments/activities (Table 3). In contrast, parents perceived the absence, or lack of such factors, to hinder smooth transition, that is, the absence or lack of planning, coordination among professionals, adolescent and adult programs, knowledge of transition, and support. Financial problems and stigma were also mentioned as barriers.

**Table 4.** Transition activities (n=30)

Transition Activities	In school n <sup>b</sup> (%)	Not in School n <sup>c</sup> (%)
Planning with Professionals	19 (86)	2 (25)
Training in daily living skills	12 (55)	7 (88)
Counseling	11 (50)	4 (50)
Contact with GOs/NGOs <sup>a</sup> for job training	10 (45)	0
Contact with potential employer	6 (27)	0
Engagement in adult leisure activities	1 (5)	2 (25)

<sup>a</sup>government organizations/non-government organizations. <sup>b</sup>n=22. <sup>c</sup>n=8.

### *Transition activities*

Respondents described measures undertaken. Varied and multiple activities were employed as shown in Table 4. Those in school utilized a more varied and broader range of activities than those already out of school. Transition planning with relevant professionals was reported by a majority. Instruction in daily living skills was reported by all of those in an out of the school environment. Parents in this group did not contact government, non-government agencies, and potential employers during the transition period. Only two parents reported planning as part of transitioning.

### *Professionals involved*

Of those whose children transitioned (n=30), they identified educators (46%) to be the predominant figures in transition. Thirty-seven percent reported the involvement of doctors. Occupational therapists and psychologists were mentioned by only 23% of the group. Thirteen percent involved family and friends. Potential employers (3%) were hardly sought out in the transition process.

## **Discussion**

This study elucidated that transition related dilemmas occur among persons with DD in the Philippines. It is a growing area of concern among families of this population. The profile of persons with DD in this study supported what is stated in literature that they are mostly unemployed. In the Philippine context, attention was drawn to one problem, which was the absence or lack of services

and programs for adolescents/adults with DD. Some degree of transition activities was slowly emerging although most were parental initiatives. It was a multiple strategy process and collaboration among service providers. There was an interaction of factors that affected the outcome of such a process. There was an apparent need to educate families and professionals on the importance of transition preparedness and development of relevant programs for this population.

### *Transition related problems*

The finding that occurrence of problems related to psychological, coping, work, and behavior areas of functioning was consistent with literature (Getzel & Kregel, 1996; McInerney & McInerney, 1994; Siporin, 1999). Work related problems such as poor attendance, difficulty acquiring new work skills, and mobility between the home and community environments suggested a lack of exposure to new environments and inadequate preparation for a post-school environment. This finding also matched with the report of Herge and Campbell (1999).

The presence of problems also showed that transition is not an easy phase for persons with DD (Chandler *et al.*, 1996; Clark & Kolstoe, 1995; Horne & Morris, 1998; Johnson, 1995; McDonnell *et al.*, 1991). Problems observed did not seem to emerge in isolation. The range of problems supported the idea that difficulties in one area were likely to affect others. Work related and coping problems were observed together with depression, and anxiety. Inability to effectively adjust in post-

school environments suggested difficulty in transferring skills to daily living situations. This gave rise to depression, anxiety, and withdrawal from family and friends. According to Moloney, Whitney-Thomas, and Dreilinger (2000), these problems may be attributed to a lack of self-definition defined as having a sense of purpose, awareness of strengths and weaknesses, and ability to convey these to others. They suggested training to include interest exploration and decision-making to facilitate acquisition of self-definition.

Environmental problems least reported by those with transition, as compared to those without, implied that even if these problems existed, transition planning and activities minimized its negative effects. This was similarly reported by Chandler *et al.* (1996); Horne and Morris (1997); Hanley-Maxwell, Whitney-Thomas *et al.* (1995).

The problems also suggested the lack of attention to the needs of adolescents and adults with DD (Getzel & Kregel, 1996; Johnson, 1995). Johnson (1995) opined that the level of “transition-readiness” affected outcome of transition programs (p.269). Considering that persons with DD achieve varying degrees of independence, timing of transition is crucial to success. Readiness to be transitioned to a post-school environment includes a critical decision that has to be made by parents and professionals involved. Measurement of outcomes related to transition varies according to set goals, levels of functioning, and cultural context. While many of the parents in this study expressed the need for transitioning for their adolescent and adult children, Filipino cultural values and beliefs influenced the final decisions in allowing their children to be more independent.

The report of these problems and the staggering number of those without transition indicated parents’ uneasiness and concern for their children’s future, which was similarly observed by Whitney-Thomas and Hanley-Maxwell (1996). Their uneasiness was made worse by the lack of knowledge and relevant services. Parents appeared to be communicating a *quiet* but desperate call for help to address employment and community adjustment requirements of their

growing children.

### *Factors affecting transition*

Parent perceptions of factors affecting transition showed a pattern of interaction among multiple factors. A relatively successful transition outcome could be predicted if most, if not all of the facilitating factors, were present (see Table 4). These factors corresponded to the essential elements of a transition program cited by Getzel and Kregel (1996); Hanley-Maxwell, Whitney-Thomas *et al.* (1995); McInerney and McInerney (1994), and O’Reilly (2000). Johnson emphasized that transition for persons with developmental disabilities requires a deliberate planning process.

Because transitioning occurs within a context, its success largely depends on close collaboration among families, service providers, professionals, agencies, and potential employers. Chandler *et al.* (1996) described the process as a “shared responsibility” (p.55).

Access to support services and work training programs is important during transition. Experience in and exposure to work environments during this period was reported to be beneficial. The case of an adult child in this study, reported to adjust successfully, was akin to the cases cited by Chandler *et al.* (1996), Kluver *et al.* (1998), and McInerney and McInerney (1994).

In contrast, the absence of those factors perceived to facilitate smooth transition turned out to be barriers. The environmental related problems cited in a previous section included a factor in transition outcomes. The scarcity or absence of options such as work, leisure, and laws had impact on the success of transition among these persons. It seemed that inadequate implementation of the Magna Carta, pervading attitudes of Filipinos, economic, and political climates continue to serve as barriers to community integration of persons with disabilities. This is not to undermine the efforts in this positive direction. To a certain extent, the Philippine government—through the Magna Carta and its agencies such as the Department of Labor and Employment, National Council for the Welfare of Disabled Persons, and various non-government organizations—has projects that have

had successful outcomes for persons with physical disabilities. However, it is still wanting for persons with DD. Major issues such as high unemployment, lack of educational and vocational opportunities, inaccessible workplaces, limited financial, and technical support continued to confront advocates of this movement (“Philippine disability scenario,” 1995–1999). Perhaps, the Philippines have yet to learn from the experiences and models initiated in developed countries such as the United States, Canada, and Japan.

### *Activities and involvement of professionals*

The scope of transition-related activities reportedly undertaken by parents and children included personal initiatives. Parents were the prime movers in the transition process. The initiative of parents to begin and be involved in the process played a significant role. Literature concurred with this finding (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995; Whitney-Thomas & Hanley-Maxwell, 1996; Schuster, Graham, & Moloney, 2000). Hanley Maxwell, Pogoloff, and Whitney-Thomas (1998) established the historic and emerging roles, and relationships of families during transition for young adults with disabilities. The network of family and friends, although not tapped by many, may be a valuable source of support and assistance in the transition process.

There was no clear and systematic protocol in activities undertaken by parents. A lack of clear guidelines, availability of, and access to transition programs was pervading. Results also suggested that there was a lack of vocational counselors, trainers, and job coaches in the Philippines. Transition is not only an issue of going through the process but also knowing *how* to go about it. This finding suggested that parents and service providers were unaware of the importance of transition. It has gained ground, however, in developed countries as reported by other professionals (Clark & Kolstoe, 1995; Horne & Morris, 1998; Johnson, 1995; McDonnell *et al.*, 1991; Schlien & Ray, 1997) and in OT literature (Ethridge *et al.*, 1989; Getzel & Kregel, 1996; Jacobs *et al.*, 1985; McInerney & McInerney, 1994; O’Reilly, 2000).

Findings of this study strongly validated that transition from school to post-school environments for young adults with DD is a turbulent time not only for them but for families as well. A shift from “child-centered” to “adult-oriented” activities that characterized this period was not an easy feat (Johnson, 1995 p. 268).

Theoretical frames have long asserted that all individuals go through life span transitions (Blair, 2000). The average person is able to traverse transition periods by accepting and managing change using internal and external resources. However, persons with developmental disabilities face additional barriers to overcome transitions. Hence, they need additional resources and support to enable them to adjust to adult life demands and be integrated successfully into their communities.

### *Study limitations*

Given that this study utilized a descriptive survey research, it is inevitable that it carries many of the inherent weaknesses of such a design. The length of the instrument, the interpretation of items, and use of mail in the collection of data may have affected response rate and interpretation of responses. Non-responses and low return rate may have affected validity and the potential for the findings of this study to be generalized to the relevant population. Also, the study did not utilize statistical tests to determine significant differences between groups.

## **Conclusions**

The dilemmas and status of transition-related activities reported in this study supported the view that the growing population of Filipino adolescents and adults with DD are underserved. Programs and services such as work training, job placement, transportation, group residences were clearly deficient, if not absent. Another significant concern is the lack of knowledge on the importance of transition.

It is imperative for occupational therapy, education practitioners, and other health professionals in the Philippines to work together in exploring and developing programs for adolescents and adults with developmental

disabilities. For Filipino occupational therapy practitioners, efforts must be exerted to shift from a modality-specific to an occupation-based practice. The lack of advocacy work toward community inclusion among government, private entities and employers remain a continuing concern. Longitudinal studies are needed to explore the nature and efficacy of transition programs in helping these persons respond appropriately to adult life demands. Understanding the process of transition in the context of Filipino and Asian culture is another research direction.

**Acknowledgements:** I thank the parents and guardians who participated in the pilot test and actual conduct of this study; the officers and staff of the Autism Society of the Philippines, Down Syndrome Association of the Philippines, and the Philippine Cerebral Palsy, Inc.; Clinic for Therapy Services; Learning Partners, Inc; Dean Susan B. Villegas, Prof. Maridel Borja; Drs. Alexis Reyes and Ria de Guzman, Ms. Josephine Nepomuceno, Mr. Rolland Lyle Duque, Ms. Hazel Pascua, Mr. Butch Regala, Ms. Yolanda Capaque, Ms. Rizalina Cruz, Ms. Fe Cagata, Ms. Mariel Apejas, Mr. Benjamin Malihan for their support and assistance.

This study was supported by the Charlotte A. Floro Professorial Chair.

A portion of this study was presented in poster format at the 13th World Congress of Occupational Therapists in Stockholm, Sweden in June 23–28, 2002.

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