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THE DEMOGRAPHIC PREDICTORS OF LOWER HEALTH PROMOTION LIFESTYLES SCORES IN CAREGIVERS OF CHILDREN WITH DISABILITIES: A QUANTITATIVE RESEARCH

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ABSTRACT

Improving the lifestyles of caregivers of children with disability helps to maintain their families' health while dealing with problems of disability, increases their quality of life. The purpose of this study was to understand the relationship of risk demographics to scores on the Health Promotion Lifestyles Profile (HPLP) and it's subscales in caregivers of children with disabilities. A cross-sectional descriptive approach with convenience sampling was used. A demographic tool and the Chinese version-HPLP was administered to 251 caregivers of children with ADHD, muscular dystrophy, or Turner syndrome in the department of pediatric psychology and genetic counseling and the Muscular Dystrophy Association of southern Taiwan. The mean age of the caregiver was 43.05 years (SD = 7.62). Scores below the 25th percentile were noted for many participating caregivers for the overall HPLP (24.3%). Based on multiple logistic regression, significant independent factors for HPLP scores below the 25th percentile included education, marital status, and residence location. Finding suggest that caregivers who are of lower income, not married, male, lower education level, and living in urban need additional support and intervention to promote healthier lifestyles.

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INTRODUCTION

Global figured estimate that 200 million children experience some form of disability, including children with single or multiple forms of physical, mental, intellectual, or sensory impairments affected by congenital diseases or acquired environments(UNESCO, 2010). Current surveys indicate that 15.1% of U.S. children have special health care needs and the parents of 24 % report at least one unmet need for services. More boys (17.4 %) than girls (12.7 %) are children with special health care needs (CSHCN), and the prevalence of CSHCN is slight higher among children with low family income (U.S. Department of Health and Human Services, Health Resources and Services, and Maternal and Child Health Bureau, 2013). In Taiwan, 1.61% of disabled children between 3 years to 12 year (29,641 persons) have some form of disability (Lai, Tseng, and Guo, 2013). For low-income people with a disability, the government share of insurance coverage is increased to 55% - 70%, further increasing to 100% for those with severe disability (Ministry of Health and Welfare, 2014).

Disabled children's physical and emotional functioning and the demands of care create strain for family caregivers and limit their ability to care for their own health needs, putting them at an increased risk for physical and emotional morbidity(Chen, Chen, Jong, Yang, and Lue, 2013; Chen and Jong, 2006. Although there is a great deal of heterogeneity in family resources (Chen and Clark, 2010) and parental adaptation to children's disability(Seltzer, Greenberg, Floyd, Pettee, and Hong, 2001) studies suggest that families of children with disabilities need more support for health promotion than general population(Hsu *et al.*, 2009; Lin, Lin, Chu, and Lin, 2011; Yen, Loh, and Lin, 2009). Relatively little is known about factors that affect the health status of parents or primary caregivers which evidence a pattern of resilience. A health promotion lifestyle is defined by Walker as a series of lifestyle behaviors by involving self-initiated actions and perceptions that serve to preserve or improve the level of wellness, fulfillment, and self-actualization of the individual (Walker, Sechrist, and Pender, 1987). Dimensions of a health promotion lifestyle include physical activity, nutrition, interpersonal relationship, stress management, health responsibility, and spiritual growth (Walker and Hill-Polerecky, 1996). Elements of a health promotion lifestyle

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include eating a healthy diet, exercising regularly, stress management, and taking responsibility for one's health (Tucker, Butler, Loyuk, Desmond, and Surrency, 2009).

Attention to health promotion would seem to contribute to the health and well-being of caregivers and be necessary for caregivers to maintain a productive life. Some studies have addressed interventions for promoting healthy lifestyles, but have generally not focused on primary caregivers of children with disabilities and the demographic predictors of health promotion lifestyle deficiencies. This study was designed to identify groups of demographic risk factors for poor health promotion behaviors to facilitate early intervention to improve health and well-being in families of children with disabilities.

We address this gap by examining four research questions. First, which effects of children's disability on parents' well-being are moderated by parental age and gender? Second, what are health promotion lifestyles and subscales scores among caregivers of children with Duchenne muscular dystrophy / spinal muscular dystrophy (DMD/SMA), attention deficiency hyperactive dystrophy (ADHD), and Turner syndrome? Third, are health promotion lifestyles scores and subscales scores related to caregivers' demographic factors? If so, what are the possible predictors that influence health promotion lifestyle and subscale scores? Examining these questions will help us better understand the variability of the impact of parenting a disabled child.

We hypothesized

- That multiple demographic factors (age, sex, education, marital status, residence location, and monthly income) would predict low overall health promotion lifestyle and subscales scores.
- Demographic risk factors (older age, male gender, low education level, no being married, urban residence, and low monthly income) will be greater predictors of low health promotion lifestyles scales scores.

Literature review

The impact of several lifestyle factors, age, weight, smoking, diet, drug use, physical inactivity, psychological stress, caffeine consumption, alcohol consumption, and exposure to environmental pollutants has been identified in the literature (Homan, Davies, and Norman, 2007; Lee, 2009). Risky health behaviors could have negative effects on both caregivers' mortality and perceived health status (Idler and Kasl, 1991). Many studies have been conducted to address caregivers' health (Haley *et al.*, 2004; Schulz and Beach, 1999), fewer published studies address caregivers' health promotion behaviors that might be influenced by parental monitoring (Rew, Arheart, Thompson, and Johnson, 2013). No consistent factors related to demographic variables or beliefs, attitudes, and knowledge have been reported as affecting health lifestyle behaviors (Anthony *et al.*, 2012; Beal, Stuijbergen, and Brown, 2009). Acton (2002) compared health promoting self-care behaviors in 46 family caregivers to 50 demographically matched non-caregivers. The researcher concluded that family caregivers scored significantly lower on the importance of self-care, health responsibility, physical activity, spiritual growth, interpersonal relationships, stress management, total health-promotion actions, and hours of sleep ($p < 0.01$).

Tang and Chen (2002) found that caregiver's educational level, perceived health status, and the care recipient's functional status were significant positive predictors of caregiver health promotion behaviors, as measured by the HPLP-II. Family caregivers with a higher level of education and better perceived health status and those who cared for stroke survivors with less disability in activities of daily living reported more participation in health promotion activities. The gender of caregivers and their relationships to care-recipients may be related to caregivers' burden, but evidence for this variable is mixed. Most studies have shown that caregiver stress tends to be higher in female caregivers (Baker and Robertson, 2008; Cantor, 1983; Collins and Jones, 1997; Pöysti *et al.*, 2012; Young and Kahana, 1989).

MATERIALS AND METHODS

Design

A cross-sectional descriptive approach and secondary data analysis was used. Informed consent was obtained from the participating caregivers by letters. This study was approved by through expedited review of the Institutional Review Board at KMU Hospital (IRB-20140059). Confidentiality was maintained during the recruitment process, questionnaire administration, data storage, and analyses.

Sample/Participants

A total of 251 caregivers, a convenience sample of families of children with ADHD (N = 108), muscular dystrophy (N = 92), or Turner syndrome (N = 51), were involved in the department of pediatric psychology and genetic counseling or Taiwan muscular dystrophy association of southern Taiwan. Criteria for inclusion in the study was that the parent, grandparent, aunt, or sibling was aged 20 or older, had a child who received an ADHD, DMD/SMA, or Turner syndrome diagnosis from a physician, and had a researcher administrated family health promotion assessment profile. Caregivers were excluded if they were less than 20 years of age, had a significant comorbidity, or were unable to communicate in Chinese or Taiwanese.

Measurements

Indicators of subjective family health lifestyle

The revised Health-promoting Lifestyle Scale (HPLP) - Chinese version (Chen, 1999) was used to collect data. The HPLP measures subjects' health promotion status based on ratings on 40 items, on a scale of 0 (never) to 5 (always). The tool has a total score range of 40 to 200, and includes six subscales related to nutrition, exercise, health responsibility, stress management, social support, and life appreciation (Beal *et al.*, 2009).

The higher the score, the better health behaviors. Chronbach's alpha for the total HPLP was 0.92; Cronbach's alphas for the subscales were 0.72 to 0.86. Cronbach's alpha above 0.70 were considered satisfactory (Polit and Beck, 2012).

Demographic characteristics

Demographic data entered the regression model in the form of dummy variables representing the effect versus the reference categories were collected at baseline using a demographic questionnaire. Participants' demographic variables included age in years; gender (coded female = 1 or male = 0); education level (coded as graduate degree = 100, bachelor's degree = 10, high school = 1, or below junior high school = 0); monthly income (coded as > NT\$ 50,000 = 10, NT\$ 30,000~50,000 = 1, < NT\$ 30,000 = 0); marital status (coded married = 1, not married = 0); residence location (coded rural and town = 1, urban = 0); and disease types (coded as Turner syndrome = 0, muscular dystrophy = 1, ADHD = 10). Avoiding collinearity, we calculated centering and mean-centering data for some continuous variables (age, all scales' scores).

Statistical Analysis

Data were analyzed using SPSS 21.0. Baseline characteristics were examined to determine differences among three disease-based groups of caregivers using chi-square test as appropriate.

Pearson correlation was used to test the relevance of all scales and subscales. Univariate analyses of variance were performed with respective baseline scores as covariates. Multiple logistic regression analysis was used to determine the predictive value of independent variables of education level, marital status, monthly income, residence location, and gender for health promotion lifestyle scores among caregivers. A likelihood ratio test was used to assess interactions of explanatory variables with the multivariate model.

RESULTS

There were 251 participants in this study, ranging in age from 20 to 64 years (mean = 43.05, SD = 7.62). Mean ages for each disease group are depicted in Table 2 as are other demographic data. Approximately five eighths (N = 160) of the participants lived in rural/town areas, and two thirds were age 40 or older (N = 172) and were female (N = 171). Almost 90% were married and approximately half of participants' monthly incomes were over NT\$ 50,000.

Table 1. The Scores and internal consistency reliability of overall HPLP and subscales scores (n = 251)

Subscale	Item number	Total score	Min ~ Max	Mean (SD)	Min ~ Max score of item	Mean of item (SD)	Cronbach's alpha
Nutrition	6	30	9~30	22.57(34.30)	1.50~3.76	3.76(0.72)	.78
Exercise	5	25	5~25	12.71(4.66)	1.00~5.00	2.54(0.93)	.86
Health responsibility	8	40	9~39	27.35(6.32)	1.13~4.88	3.43(0.79)	.84
Stress management	6	30	6~30	20.98(4.23)	1.00~5.00	3.50(0.71)	.76
Social support	7	35	11~35	25.80(4.90)	1.57~5.00	3.68(0.70)	.85
Life appreciation	8	40	11~40	29.14(6.28)	1.38~5.00	3.64(0.79)	.92
Overall HPLP	40	200	67~194	138.53(23.74)	1.62~4.85	3.43(0.59)	.95

Table 2. Demography characteristics of study participants, total sample, and by disease type

Variable		Total (N=251)		Disease Type				Chi-square p-value	
		n	%	ADHD (N=108)		DMD/SMA (N=92)			Turner syndrome (N=51)
				n	%	n	%	n	%
Age (years)	Mean (SD)	43.05 (7.62)		40.67 (5.91)		45.12 (8.70)		44.35 (7.49)	
	min ~ max	20~64		26~59		20~64		24~61	
Age level	< 40 years	80	31.87	43	39.81	21	22.83	16	31.37
	>= 40 years	171	68.13	65	60.19	71	77.17	35	68.63
Gender	Female	172	68.53	83	76.85	58	63.04	31	60.78
	Male	79	31.47	25	23.15	34	36.96	20	39.22
Education	Graduate	43	17.13	16	14.81	15	16.30	12	23.53
	Bachelor	64	25.50	29	26.85	18	19.57	17	33.33
	High school	101	40.24	50	46.30	35	38.04	16	31.37
	< Junior high school	43	17.13	13	12.04	24	26.09	6	11.76
Marital status	Married	217	86.45	95	87.96	76	82.61	46	90.20
	No married	34	13.55	13	12.04	16	17.39	5	9.80
Monthly income	> NT\$ 50000	124	49.40	51	47.22	36	39.13	37	72.55
	NT\$ 30000~50000	64	25.50	24	22.22	30	32.61	10	19.61
	< NT\$ 30000	63	25.10	33	30.56	26	28.26	4	7.84
Residence location	Urban	91	36.25	29	26.85	48	52.17	14	27.45
	Rural and town	160	63.75	79	73.15	44	47.83	37	72.55

Descriptive statistics, mean scores and standard deviation (SD) were used to describe continuous variables (e.g. age, total HPLP, subscale scores, each item score on the six HPLP subscales). Chi-square was used to compare the categorical variables (e.g., sex, monthly income, marital status, education level, residence location) in the three disease groups.

Two fifths of caregivers were educated at high school level, and about one half had a bachelor's or graduate degree. Nearly half (43.0%) of participants who completed the questionnaires had children with DMD/SMA, 36.7% had a child with ADHD, and 20.3% had a child with Turner syndrome. More participants in DMD/SMA group were over age 40 than in the other groups.

Table 3. Prevalence of low health promotion lifestyles scores among study participants

Variable		Total	Disease Type								Chi-square p-value
			ADHD		DMD/SMA		Turner syndrome				
Subscales	Group	scores	n	%	n	%	n	%	n	%	
Nutrition	low score	< 20	58	23.11	27	25.00	24	26.09	7	13.7	0.2
	non-low score	≥ 20	193	76.89	81	75.00	68	73.91	44	86.27	
Exercise	low score	< 9	52	20.72	16	14.81	26	28.26	10	19.61	0.06
	non-low score	≥ 9	199	79.28	92	85.19	66	71.74	41	80.39	
Health responsibility	low score	< 23	60	23.9	29	26.85	27	29.35	4	7.84	0.01
	non-low score	≥ 23	191	76.1	79	73.15	65	70.65	47	92.16	
Stress management	low score	< 18	45	17.93	22	20.37	20	21.74	3	5.88	0.04
	non-low score	≥ 18	206	82.07	86	79.63	72	78.26	48	94.12	
Social support	low score	< 23	61	24.3	24	22.22	29	31.52	8	15.69	0.09
	non-low score	≥ 23	190	75.7	84	77.78	63	68.48	43	84.31	
Life appreciate	low score	< 25	53	21.12	29	26.85	20	21.74	4	7.84	0.02
	non-low score	≥ 25	198	78.88	79	73.15	72	78.26	47	92.16	
Overall Health promotion lifestyle	low score	<123	61	24.3	27	25	29	31.52	5	9.8	0.02
	non-low score	≥123	190	75.7	81	75	63	68.48	46	90.2	

Notes: Low score group < 25 percentile, Non-low score group ≥ 25 percentile.

Table 4. Results of multiple logistic regression of HPLP scores and demographic variables

Variables	Low score group		High score group		OR	95% CI		P-value	
	n	%	n	%		lower	upper		
Total	61	100	190	100					
Education	Graduate	6	9.8	37	19.47	1			
	Bachelor	10	16.4	54	28.42	1.40	0.44	4.41	0.57
	High school	26	42.6	75	39.47	2.32	0.83	6.50	0.11
	< Junior high school	19	31.15	24	12.63	5.18	1.69	15.85	<0.01
Marital status	Married	44	72.13	173	91.05	1			
	Not married	17	27.87	17	8.95	4.81	2.13	10.86	<0.01
Residence location	Ural/town	29	47.54	131	68.95	1			
	Urban	32	52.46	59	31.05	2.4	1.27	4.54	<0.01

HPLP total score = 200, mean = 138.53 ± 23.74, min to max = 67~194,

Low score group: HPLP: < 25 percentile of score, score < 123;

High score group: HPLP: ≥ 25 percentile, score ≥ 123.

Overall prediction accuracy is 79.3%.

More participants in ADHD group were female, education at high school, lived in rural/town areas, and had monthly income greater than NT\$ 50,000 than in the other groups (Table 2). There were significant differences in high risk of low overall health promotion lifestyle among the three disease types, with fewer parents of children with Turner syndrome exhibiting low scores. There here were no significant differences among three disease types in risk for low nutrition, exercise, or social support scores (below the 25th percentile) (Table 3). However, caregivers of children with Turner syndrome were significantly less likely to exhibit low scores (below the 25th percentile) for health responsibility, stress management, social support, and life appreciation than those for children with ADHD or muscular dystrophy (Table 3). The mean HPLP score was 138.53 (SD = 23.74), and the mean item score for the entire scale was 3.43 (SD = .59). Mean item scores for the HPLP subscales ranged from 2.54 to 3.76 (SD = 0.59 – 0.93). Stepwise logistic regression was used to compare demographic factors associated with HPLP scores below and at or above the 25th percentile.

Factors associated with low scores are presented in Table 4 and included low education level, not being married, and living in an urban setting. The overall predictive value of this model was 79.3%. For the nutrition subscale, monthly income predicted caregivers' lower nutrition scores with an overall predictive accuracy of 76.9 % (Table 5). Monthly income was also the major factor predicting stress management and life appreciation subscale scores, with predictive values of 82.1% and 79.8%. Not being married and living in an urban setting predicted low exercise subscale scores, and living in an urban locale and male gender were associated with low health responsibility subscale scores. Not surprisingly, not being married was also associated with low social support subscale scores.

DISCUSSION

Main findings

The study was conducted to assess health promotion lifestyle and its dimensions among caregivers of children with

Table 5. Results of multiple regression models of HPLP subscales scores and demographic variables (I)

Subscale Variables	Low score group		Non-low score group		OR	95% CI		P-value	Prediction accuracy
	n	%	n	%		lower	upper		
Nutrition (M = 22.75, SD = 4.30, low score < 20, high score >= 20, range = 9 - 30)									
Monthly income	58		193						
> NT\$ 50000	17	29.31	107	55.44	1				76.90%
NT\$ 30000~50000	16	27.59	48	24.87	2.1	0.98	4.5	0.06	
< NT\$ 30000	25	43.1	38	19.69	4.14	2.02	8.5	<.001	
Stress management (M = 20.98, SD = 4.23, low score < 18, high score >= 18, range = 6- 30)									
Monthly income	45		206						
> NT\$ 50000	13	28.89	111	53.88	1				82.10%
NT\$ 30000~50000	17	37.78	47	22.82	2.668	1.18	6.036	0.02	
< NT\$ 30000	15	33.33	48	23.3	3.088	1.39	6.864	<.01	
Life appreciation (M = 29.14, SD =6.28, low score < 25, high score >= 25, range = 11- 40)									
Monthly income	53		198						
> NT\$ 50000	20	37.74	104	52.53	1				78.90%
NT\$ 30000~50000	11	20.75	53	26.77	1.08	0.48	2.42	0.85	
< NT\$ 30000	22	41.51	41	20.71	2.79	1.38	5.65	<.01	

Table 5. Results of multiple regression models of HPLP subscales scores and demographic variables (II)

Variables	Low score group		High score group		OR	95% CI		P-value	Prediction accuracy
	n	%	n	%		lower	upper		
Exercise (M = 12.71, SD = 4.66, low score < 9, high score >= 9, range = 5 - 25)									
	52		199						
Marital status	40	76.92	177	88.94	1				78.90%
Not married	12	23.08	22	11.06	2.64	1.18	5.9	0.02	
Residence location	24	46.15	136	68.34	1				
Urban	28	53.85	63	31.66	0.38	0.20	0.71	<.01	
Health Responsibility (M = 27.35, SD = 6.32, low score < 23, high score >= 23, range = 9 - 39)									
	60		191						
Gender	33	55	139	72.77	1				76.10%
Male	27	45	52	27.23	2.13	1.16	3.91	0.02	
Residence location	29	48.33	131	68.59	1				
Urban	31	51.67	60	31.41	2.28	1.25	4.15	0.01	
Social support (M = 25.80, SD = 4.90, low score < 23, high score >= 23, range = 11 - 35)									
	61		190						
Marital status	46	75.4	171	90	1				75.50%
Not married	15	24.6	19	10	2.94	1.39	6.22	<.01	

disabilities to identify factors predictive of low health promotion scores (below the 25th percentile). Mean item scores on the HPFP were higher than those reported in Lo's (2009) and Beal's *et al.* (2009) reports of 2.44 (.38) and 2.61 (.39), respectively. In this study, participants' highest scores were on the nutrition subscale, followed by the social support and life appreciation subscales, with the lowest score related to exercise - a finding similar to that of Beal *et al.* (2009). Similar findings regarding nutrition and exercise were found by Mirghafourvand *et al.* (2014) and Tucker *et al.* (2009) but results for other dimensions of the HPLP differed from the current findings. Prior evidence indicated that education, income, and residence location were associated with total scores on the health promotion lifestyle tool (Mirghafourvand *et al.*, 2014). The role of income was reported by Robinson (1990) who found that caregivers with higher income were better prepared to cope with health care responsibilities and engage in health promoting behaviors (Fukuda, Nakamura, and Takano, 2005; Ng *et al.*, 2012). As caregivers facilitate and maintain their caregiving role, finances will be one of the important factors in adaptation (Sinha, 2013).

Low income limits the potential for healthy food selections (Guenther, Reedy, and Krebs-Smith, 2008) and the ability to take responsibility for one's own health (Seehera, Iowa, Reppermunde, and Brodatya, 2013). Those findings were consistent with low nutrition scores in those with incomes under NT \$ 30,000 in the present study. We also found that low income was associated with lower life appreciation and stress management scores. The findings of the study confirmed that education, income, and residence location acted as major risk factors for low HPLP scores similar to previous study report (Board on Neuroscience and Behavioral Health, 2010; Mirghafourvand *et al.*, 2014; Ng *et al.*, 2012). Caregivers who had lower education levels were more likely to report low scores on the HPLP than those with graduate education. Other studies, however did not report significant differences (Anthony *et al.*, 2012; Beal *et al.*, 2009). In the present study, different diseases experienced by children had different effects on health promotion lifestyle and its dimensions of health responsibility, stress management, and life appreciation. Caregivers who were not married were more likely to report low scores on the HPLP and on subscale scores for exercise and social support than those who were married. These results were not in accord with Beal's *et al.* (2009) report. Most studies used marital quality as the major predictors of caregivers' psychological symptoms, stress management, and social support (Seehera *et al.*, 2013).

Residence location in an urban setting was also strongly associated with a low overall HPLP score as well as low scores for health responsibility and higher scores for exercise. Fukuda (2005) also reported that region of residence was a stronger predictor of risky health behaviors for females than males. Another study found that mothers were at an increased risk for stress and poor health compared to fathers (McConkey, Truesdale-Kennedy, Chang, Jarrah, and Shukri, 2008) as a result of having a child with a disability. However, the current study found that males demonstrated lower scores on health responsibility than females. Like Beal *et al.*'s (2009) findings, caretaker age was not significantly related to HPLP scores. This differed from previous study findings in which age over

45 years was a risk factor for lack of health promotion (Chen and Lin, 2010). When disability service systems attempt to support families, their role should be to help family systems function better by focusing on improving the quality of multiple aspects of family life. However, because disability service systems are sometimes more concerned with curtailing expenses than doing what is necessary to improve quality of family life, their interventions can be ineffective in supporting family units in positive ways (Samuel, Rillotta, and Brown, 2012). Tailoring interventions to reflect demographic factors that predict need may serve to meet both service and cost-containment goals.

Strength and limitation

One of the strengths of this study was recruiting participants from several disease categories, who might not otherwise studied. Although, participation was not randomized the sample was large enough to identify differences among groups using basic statistics. A study limitation was the fact that a third of possible subjects refused participation for reasons of lack of time, work overload, privacy concerns, or lack of interest. Researchers continued to select participants with the goal of achieving a sample that was representative of the disabled child population for the three diseases included. Future study should include qualitative approaches using deep interviews to promote generalization of findings and identify gaps in research evidence. Based on these preliminary findings, however, caregivers of children with disabilities who are of lower income or education level, not married, male, and living in urban settings can be specifically targeted for increased support and intervention to promote nutrition, exercise, stress management, social support, health responsibility, and life appreciation. Early identification and linking of these potentially high-risk families to effective support services can improve their quality of life and overall family well-being.

Contribution

Demographic variables, such as education, gender, marital status, residence location, and monthly income, are known to influence health promotion lifestyles including nutrition, exercise, health responsibility, stress management, social support, and life appreciate. Low social economic status, which incorporates a low level education, low income, and urban living, is associated with less health promotion life styles. Therefore, interventions programs for health promotion lifestyles must focus on disadvantaged caregivers.

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