Importance of Quality of Life Issues: A Pilot Comparison of Teachers and Parents of Children with Autism Spectrum Disorders

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Abstract

Quality of life (QoL) issues for parents and teachers of children with autism spectrum disorders (ASD) are important to investigate. Independence, social functioning, school functioning and participating in leisure activities are some of the quality of life indicators that parents and teachers must agree upon to ensure effective communication and goal-setting. The purpose of the current study was to compare the perspectives of parents and teachers of children with ASD with regard to the importance of quality of life issues. Participants for this study consisted of parents and teachers of children with ASD. Results indicate that often, parents and teachers have different QoL goals for children and students with autism spectrum disorders. These differences in goals can be a complex issue and could result in discrepancies in how we educate individuals with ASD.

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Quality of Life (QoL) is a measure of a person’s overall wellbeing. This construct is influenced by many factors (Sipos, Predescu, Muresan, & Iftene, 2012; Lee, Harrington, Louie, & Newschaffer, 2008). QoL includes multiple domains including a person’s perception and self-confidence while taking part in socially respected roles that are seen by others as competent (Lee, Harrington, Louie, & Newschaffer, 2008; Ruble & Dalrymple, 1996) and encompasses factors related to well being (Sipos et al, 2012; Pimley, 2007). QoL is recognized as an important construct in researching developmental disabilities (Lee et al, 2008). A major focus of both parenting and teaching a child with a developmental disability is to ensure that the child obtains the best quality of life possible. This study investigates the perspectives of both parents and teachers of children with an autism spectrum disorder regarding the different aspects of quality of life. Burgess & Gutstein (2007) have indicated that quality of life should be the framework for building programs, offering services, and assessing environments.

Some quality of life indicators to consider when judging outcomes for individuals with ASD can include: (1) participation in activities with family and friends, (2) contact with family members as frequently as desired to include events and passages (birthday parties, weddings, funerals), (3) being active and comfortable in a familiar community (transportation, shopping), (4) working at a valued job to earn money, (5) learning about the world through successful experiences with supportive people (opportunity to try new activities and challenges), (6) taking responsibility for personal and home chores and contributing to the family, (7) making choices about purchases, and (8) having his/her own possessions to keep as desired. Johnson, Fremm, Fetham, & Simpson (2011) add that these indicators are based on a person's beliefs, perceptions and expectations. Acknowledging quality of life and rights for children with disabilities reiterates that having access to and receiving a free and appropriate education, preparation for employment, and recreational opportunities is critical for these children in order to integrate socially and develop as individuals to the fullest extent possible. With the passage of Americans with Disabilities Act of 1990 (ADA), P.L. 101-336, persons with disabilities may no longer be discriminated against in public services such as libraries, public restaurants, public transportation, and recreation programs. In addition, ADA emphasizes that employers must make "reasonable accommodations" to enable prospective employees to perform the basic responsibilities of the job.

Although previous legislation was geared toward assuring equal access and stopping discrimination against persons with disabilities, persons with autism have not benefited from these protections in the area of education until recently. Although recognized as early as the beginning of the 20th century, autism, a pervasive developmental disorder, was not categorized as a disability until the reauthorization of Individuals with Disability Act (IDEA) in 1990. This reauthorization created an additional category, mandated by law, which entitles children with ASD to receive all legal benefits. This additional category also acknowledges that children with ASD are a separate category within the IDEA disability umbrella.

With the IDEA of 1997, there are greater expectations for children with special needs. Congress has emphasized its focus on outcomes to assist children with special needs to become contributing and participating members of the community (Cappe, Wolff, Bobet, & Adrien, 2011; Autin, 1999). In addition, legislation dealing with inclusion has had a major effect on how children with special needs are accommodated in the classroom. The current literature reports that the ability of professionals to work with a child relies upon the critical component that they can work with the families as a system (Smith, Myles, Aspy, Grossman, & Henry, 2010; Gray, 1998; Simpson, 1990; Van Haren & Fiedler, 2008; Wetherby & Prizant, 2000).

Because today many children are increasingly being diagnosed with autism (Frederick, Barnard-Brak, Sulak, 2012; Center for Disease Control 2008; Hardman, Drew, & Egan, 1999; Huebner& Dunn, 2001; Lord & Risi, 2000; Sicile-Kira, 2004), there are increased educational concerns about quality of life (QOL). Professionals in the field of education must consider QOL and the importance of issues related to QOL. In addition, parents are concerned about QOL for their children. If parents and teachers are similar in their ideas regarding the importance of quality of life concerns, there may be a better chance of an effective collaborative relationship. However, if the ideas of parents and teachers are dissimilar, educational issues could go unresolved, resulting in conflict. This may serve to compromise the quality of the education for the child with autism (Cappe, Wolff, Bobet, & Adrien, 2011). With an increasing number of diagnoses and no known cure for autism, educational placement and services have the potential to become a major issue with regards to educational interventions and future success and outcomes in children with ASD

(Cappe et al, 2011; Bitterman, Daley, Misra, Carlson, & Markowitz, 2008; Kellegrew, 1995; Simpson & Myles, 1998).

Ruble & Dalrymple (1996) investigated forty-six individuals with autism. In this study, outcomes were addressed in a new framework that consists of a) a person's strengths and challenges, b) other's perceptions of competence, c) self-perceptions of quality of life, and d) environmental stressors and supports. Exploration of new ways to define and broaden views of outcomes, specifically with autism, was targeted. In addition, the researchers emphasize that professionals need to communicate with parents regarding the importance of competence and its relationship to quality of life. Quality of life domains provide a framework for determining the impact of autism in a way that does not merely look at symptoms. In addition, Lee, Harrington, Louie & Newschaffer (2008) Studies have reported that parents of children with ASD, no matter what their ages, had serious doubts about their children's well-being and, consequently, QOL issues (Sipos et al, 2012; Lee et al, 2008). Therefore, QOL is a critical component for parents and teachers who have or work with children who have an ASD.

The purpose of the current study was to investigate and compare the perspectives of parents and teachers of children with ASD with regard to the importance of quality of life issues. Nissenbaum, Tollefson & Reese (2002), state that there is an absence of research on the topic of relationships between families and professionals of children with ASD. When discussing the education of children with special needs, including children with ASD, the beliefs of parents and teachers must be included in that discussion. Research has consistently shown that both parents and teachers have a significant impact on the future of children with ASD. In response to the lack of research that compares beliefs of parents and teachers, this study investigated the extent to which parents' and teachers' ratings differed for QOL issues for children with ASD.

Method

Participants

Participants for this study were drawn from a population consisting of both parents and teachers of children with ASD in 2 mid-western states. Through convenience sampling a total of 15 teachers and 25 parents were surveyed. Convenience sampling is a type of purposeful sampling (Gay, Mills, & Airasian, 2009; Mertens &McLaughlin, 1995) and it is often utilized with research conducted with special education populations. Therefore, teachers in both public and private settings were selected based on geographical location.

Although this is a relatively small sample size and was chosen by availability, there is evidence that the sample is representative of the general population of parents and teachers of children with autism (Marszalek, Barber, Kohlhart, & Holmes, 2011). Both public and private school settings are represented in the participant groups. The children associated with this study had a variety of diagnoses within the autism spectrum (ASD, Asperger's and Rhett's).

The first portion of the instrument contained questions to enable the researcher to obtain demographic information about each of the participants. Information elicited from parents or guardians included relationship to the child, type of school placement, ethnicity, and location of residence. Information elicited from teachers included gender of the teacher, type of school employment, years of teaching experience, ethnicity, and location of school.

Parents. Twenty-five parents responded to the survey. The children had been diagnosed with developmental disabilities that included mild to severe Autism, Asperger's Syndrome, Rhett's Syndrome or Pervasive Developmental Disability. All parents resided in 2 mid-western states.

One father, 21 mothers, and 1 aunt participated in this study. In two cases the mother and father completed the survey together. Information about the parents who completed this survey is given in Table 1 below.

Table 1
Demographics of Parent Participants

Relationship		
Mother	21	(84%)
Father	1	(4%)
Other (Aunt)	1	(4%)
Both	2	(8%)
Ethnicity		
African American	4	(16%)
Asian American	1	(4%)
Caucasian	17	(68%)
Hispanic	3	(12%)
Native American	0	
Location of Residence		
Urban	17	(68%)
Suburban	4	(16%)
Rural	3	(12%)

The majority of the parents were Caucasian (17). Four parents were African American, 3 were Hispanic, and 1 was Asian American. At the time of the study, seventeen parents resided in an urban setting, 4 lived in a suburban setting, and 3 lived in a rural area.

Teachers. The sample of 15 teachers was selected from schools in the rural and urban mid-west. All of the teachers worked with children with ASD of all levels.

Of the 15 teachers, 14 were female. Fourteen of the teachers were Caucasian and 1 was African American. Almost half of them (47%) have taught 5 years or less. Fifty-three percent have taught 6 years or more. Ten of the 15 teach in urban settings, 3 teach in suburban settings, and 2 teach in rural areas. Table 2 below shows the demographic information regarding the teachers who participated in this study.

Table 2
Demographics of Teacher Participants

Gender		
Male	1	(6%)
Female	14	(93%)
Years of Teaching		
1-5	7	(46%)
6-10	2	(13%)
Over 10+	6	(40%)
Ethnicity		
African American	1	(7%)
Asian American		0
Caucasian	14	(93%)
Hispanic		0
Native American		0
Location of School		
Urban	10	(67%)
Suburban	3	(20%)
Rural	2	(13%)

Children with ASD. The demographics given in Table 3 reflect age, diagnosis, ethnicity, and any other disabilities, as reported by teachers and parents in this study. Of the 40 children targeted, ages ranged from 4 through 21 years. The ethnicity included 5 children from African American backgrounds, 31 Caucasian backgrounds, 3 from Hispanic backgrounds and 1 from an Asian American background.

Table 3
Targeted Children with Autism

	Parents	Teachers	Total
Age			
1-5	4 (16%)	1 (7%)	5 (13%)
6-10	17 (68%)	8 (53%)	25 (63%)
11-15	2 (8%)	3 (20%)	5 (13%)
16-20	1 (4%)	3 (20%)	4 (10%)
Diagnosis			
Mild Autism	8 (32%)	2 (13%)	10 (25%)
Moderate Autism	6 (24%)	7 (47%)	13 (33%)

Severe Autism	6 (24%)	4 (27%)	10 (25%)
Asperger's Syndrome	4 (16%)	2 (13%)	6 (15%)
Rhett's Syndrome	1 (4%)	0	1 (3%)
Ethnicity			
African American	4 (16%)	1 (7%)	5 (13%)
Asian American	1 (4%)	0	1 (3%)
Caucasian	17 (68%)	14 (93%)	31 (78%)
Hispanic	3 (12%)	0	3 (8%)
Native American	0	0	0
Other Disabilities			
Yes	8 (32%)	12 (80%)	20 (50%)
No	17 (68%)	3 (20%)	20 (50%)

Diagnoses indicated 10 children with mild autism, 13 with moderate autism, and 10 with severe autism, for a total of 83%. Asperger's Syndrome was reported in 6 of the children and Rhett's Syndrome was reported in 1 of the children, according to teachers and parents.

Instrument

The 20-statement instrument that was used in this study was adapted from Mutua (1999) with the purpose of collecting data about teachers' and parents' ratings of quality of life issues. Parents and teachers were asked to rate how important it is for them that their child/student achieves the future outcome specified by each item derived from theory on autism. The responses were scored on a 5-point scale from highly unimportant (1) to very important (5). Likewise, with regard to likelihood of expectations, responses were scored on the same scale, a 5-point Likert-type scale ranging from highly unlikely (1) to very likely (5). This instrument was appropriate for this particular study since it was used in the recent past to investigate expectations for children with disabilities, including that of autism (Mutua & Dimitrov, 2001; Mutua, Miller, Mwavita, 2002).

Since the survey used a Likert-type scale, Cronbach's Alpha was used to assess internal consistency. The data were determined to have a reliability coefficient of .90 for the Importance of Expectations and .93 for Likelihood of Expectations. The reliability coefficient for the data as a whole was .91. These high alpha values indicate that the instrument and its parts measure the same characteristics. This is consistent with the reliabilities for importance and likelihood (.90 and .93, respectively) reported by Mutua (1999). In addition, Mutua used exploratory factor analysis (EFA) to study the nature of the theoretical factors on expectations of importance. She found that the survey was composed of factors with a high correlation and content equivalency across their ratings. These four factors were adult roles, importance of community and civil access, importance of educational attainment, and importance of personal fulfillment.

Procedure

The researcher received permission from the superintendents prior to conducting the study. Informed consent was obtained from all participants' parents or guardians. The surveys were distributed to the teachers and parents by the investigator. Participants were instructed to return the surveys to the researcher within two weeks. Stamped envelopes were provided if the teachers and parents chose to mail the responses to the investigator.

Data Analysis

Parents' and teachers' ratings of the QOL issues for children with autism were the focus of this study. The analysis was computed using SPSS statistical package. The research questions guided the data analysis.

Since the two groups were drawn from different populations, an independent-samples t-test was calculated for each construct to determine if the means of parent responses differed significantly from that of teacher responses. Levene’s Test for Equality of Variances was calculated to see if the spread of the two groups differed. If the significance level for this test was low (less than 0.05), the separate-variance t-test was used. If Levene’s Test showed that the variances were equal (the distributions have the same shape), a pooled-variance t-test was used. The 95% confidence interval was calculated for each comparison.

Sample size is always a concern in research studies. When comparing responses of parents and teachers it should be noted that there were 25 parents and 15 teachers. However, research (Marszalek et al, 2011; Delaney & Vargha (2000) and Sawilowsky & Hillman (1992) supports the acceptability of the ratio of parents and teachers in this study.

Results

Parents' and teachers' ratings of importance of QOL issues for children with autism were the focus of this study. The construct examined was the issue of importance with QOL as expressed by the responses of both parents and teachers. The means and standard deviations for the parents and teachers are given in Table 4 below.

Table 4
Means and Standard Deviations of Teachers’ and Parents’ Responses

Statement	Parent		Teacher	
My child/student with autism will be…	M	SD	M	SD
1. …happy and satisfied	4.72	.54	4.60	.63
2. …attend school.	4.96	.20	4.93	.26
3. …get married.	3.44	1.42	2.27	1.22
4. …own a house.	3.56	1.26	2.07	1.28
5. …support network of friends.	4.68	.56	4.47	.92
6. …religion of choice.	3.92	1.19	3.40	1.45
7. …accepted in the community.	4.56	.65	4.87	.35
8. …secure financial future.	4.68	.48	4.33	.82
9. …safe from physical harm.	4.92	.28	5.00	.00
10. …highest education possible.	4.68	.75	4.80	.77
11. …help with household chores.	4.44	.77	4.87	.35
12. …socially responsible/law abiding.	4.64	.49	4.73	.59

13. …take care of parent in old age.	1.56	.77	2.13	1.19
14. …participate in citizenship activities.	3.44	1.12	3.80	.77
15. …live independently..	4.40	.65	3.93	.92
16. …time to play/watch games.	4.40	.71	4.60	.63
17. …hold a job/vocation.	4.64	.57	4.67	.72
18. …have own children.	2.96	1.59	1.73	.96
19. …use community services.	4.24	.72	4.60	.83
20. …be successful in school.	4.60	71	4.47	1.13

For parents, the means ranged from 1.58 for statement 13 (…take care of parents in old age) to 4.96 for statement 2 (…attend school). The mean for statement 18 (…have own children) was the second lowest mean (2.96). The rest of the statements had means equal to or greater than 3.44.

For the teachers, the means ranged from 1.73 for statement 18 (…have own children) to 5.00 for statement 9 (…safe from physical harm). Close to the high of 5.00 was the mean 4.93 for statement 2 (…attend school). The means for several other statements were low (2.27 or lower): statement 3 (…get married), statement 4 (…own a house), and statement 13 (…take care of parents in old age). The rest of the statements had means equal to or greater than 3.40.

There were four statistically significant differences as a result of the t-test. These results are given in Table 5.

Table 5
Results of Independent-Sample t-test

Statements	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference		t	df	Sig.(2-tailed)
			Lower	Upper			
1	-.12	.19	-.50	.26	-.64	38	.528
2	- .03	.07	-.17	.12	-.37	38	.717
3	- .17	.44	-2.07	-.28	-.66	38	.011*
4	-1.49	.41	-2.33	-.66	-.61	38	.001**
5	- .21	.23	- .68	.20	-.92	38	.364
6	- .52	.42	-1.37	.33	-.23	38	.225
7	.31	.16	- .01	.63	1.93	37.7	.061
8	-.35	.20	-.76	.07	-1.70	38	.097
9	.08	.06	- .03	.23	1.45	24	.161
10	.12	.25	-.38	.62	.49	38	.631
11	.43	.18	.06	.79	2.39	36.1	.022*
12	.09	.17	.26	.44	.54	38	.593
13	.57	.39	-.05	1.20	1.86	38	.071
14	.63	.30	.25	.97	1.20	37.1	.238
15	-.47	.25	.98	.04	-1.88	37	.068
16	.20	.22	.25	.65	.90	38	.374
17	.03	.21	.39	.44	.13	38	.898

18	-.23	.40	-.05	-.41	-3.04	37.9	.004**
19	.36	.25	.15	.87	1.44	38	.157
20	-.13	.29	.72	.45	-.46	38	647

*p< .05. **p< .01

Two of these, statement 4 (…own a house) and statement 18 (…have own children), were significant at the .01 level while two, statement 3 (…get married) and statement 11(…help with household chores), were significant at the .05 level. For all of the significantly different responses, except for statement 11, the parents articulated a higher degree of importance than did the teachers. The importance for statement 11 was greater for the teachers.

For the remaining statements there were no statistical significances found for parent and teacher responses. There were no significant differences in statement 1 (…being happy and satisfied), statement 2 (…will attend school), statement 5 (…network of friends), statement 6 (…religion of choice), statement 7 (accepted in the community), statement 8 (secure financial future), statement 9 (…safe from physical harm), statement 10 (highest education possible), statement 12 (…socially responsible/law abiding), statement 13 (…take care of parents in old age), statement 14 (…participate in citizenship activities), statement 15 (…live independently), statement 16 (…have time to play/watch games) statement 17 (…hold job/vocation), statement 19 (…use community services), and statement 20 (…be successful in school).

Discussion

The purpose of this study was to determine to what extent parents' and teachers' differ in their ratings of importance of quality of life issues for children with autism. The views of both groups have validity. These groups see children in different settings that affect the children in different ways. Therefore, the two groups may provide mutually exclusive perspectives on the importance of QOL issues.

For the parents, the lowest means were for the concept of taking care of parents in their old age. Due to the fact that parents (63%) who responded in this study have children as young as age 4 years, the parents may not feel a child this young could actually care for them. It is possible that parents are relying on siblings to burden the responsibility of caring for them when they are old. Possibly related to this inability to care for others is the response to the statement about having children. Parents may feel that their child with ASD lacks the capacity to be a caregiver, whether for elderly parents or children.

Parents responded that school attendance issues are very important. Schools offer parents of children with ASD assistance with academic and vocational education as well as daily living skills. Much of the parental support comes from the schools. Parents indicated that the services and programs available are important and needed.

Teachers indicated that their most important expectation for their students is that they are safe in society and will experience no bodily harm. In addition, the teachers put a high degree of importance on attending school. All the participants were employed as teachers in the field, giving weight to the value of education and its related interventions for children with autism.

Teachers did not feel that having children is an important aspect in life for a student with ASD. Teachers indicated that basic academics, daily living skills, and communication skills are more critical than raising children. Further, teachers did not think a student with autism should concentrate on taking care of other adults such as parents and probably would not have the appropriate skills to do so.

Although there were four statements for which there were statistically different means for the responses, numerically some of the means were quite different. For the importance of getting married, the mean for the parents' responses was one of the highest while the mean for the teachers' responses was one of the lowest. For the statement concerning the importance of acquiring his or her own home, the mean for parents' responses was high while the mean for the teachers' responses was low. Although the means differed significantly, they were not extremely high or low.

Both parents and teachers were generally positive about the importance of participating with chores although the teachers' means were significantly higher than the means of the parents. For the concept of having children, the means for both groups were significantly different but both were relatively low.

The three statements that the parents ranked as significantly higher than did the teachers (get married, own a house, and have own children), represent the hopes of most parents for their children. Teachers did not see the students in a home and family environment on a daily basis; therefore they did not see these QOL issues as critical. However, concerning the item about household chores, the teachers commonly included the daily-living skills in the residential setting as well as part of the classroom curriculum for students with low incidence disabilities. Therefore, this would be a critical issue for teachers. For parents, there are often other people, such as siblings, in the family that can assist with these duties other than the child with ASD.

There were several statements for which there was no statistical significance found between parent and teacher responses. The parents and teachers agreed on the importance of being a contributing member of society such as having friends, participating in citizenship activities, being responsible, and being accepted in the community. Additionally, both groups also viewed being a law-abiding citizen and being employed as important for the individual with ASD. There was also agreement on the importance of well-being QOL issues such as being safe, using community services, being happy, and having a secure financial future. Pimley (2007) found that QOL issues of social and community relationships may be influenced by the desire of children with ASD to live with as few social contacts as possible. In this study both parents and teachers were very positive about the importance of this topic.

Parents and teachers also agreed that the self-choice issue of religion was important. Educational issues were important to both parents and teachers. Although parents and teachers agreed on the importance of living independently (parents: M=4.40; teachers: M =3.93),and taking care of parents in old age (parents: M= 1.56; teachers: M = 2.13), there was a large, although not statistically significant, discrepancy in the means of the two statements. The means of the responses for caring for elderly parents were very low(parents: M= 1.56; teachers: M = 2.13).

Also low were the means for the possibility of having children (parents: M = 2.96; teachers: M =1.73).

Implications

The purpose of this study was to investigate the extent to which differences exist on parent and teacher ratings of the importance of quality of life issues. It is critical to understand the issues related to quality of life issues for children with an autism spectrum disorder. Parents and educators alike have been assigned the difficult tasks of preparing these children for an independent, satisfying life and future. Through examining the commonalties and differences between parents and educators, one gains a clearer understanding of the perspectives of both. The parents expressed a much higher importance on family issues, such as marriage, establishing a home, and having children than did the teachers. Teachers expressed a much higher importance on independence and daily-living skills. Increased awareness of both perspectives enables both to create better strategies for improved quality of life outcomes in children with an ASD.

When considering the domains of QOL, it is important to take into consideration all potential service providers. By expanding our knowledge of how autism impacts the QOL of not only individuals with autism, but also their family members, support and services can be developed for children and families. No one would argue against the fact that families of children with ASD need support. These findings convey to service providers which QOL issues are deemed important to parents. This allows the providers a clear picture of the insight and beliefs within the family system. Therefore, these expectations should be incorporated into service delivery when appropriate. More specifically, professionals in the medical field should consider QOL when investigating treatment options. Meaningful dialogues are important in addressing parental beliefs about QOL issues.

In a clinical setting, QOL issues can play a role in intervention decisions based on the family values (Lee et al, 2008; Bailey & Simeonsson, 1988). This will help the engagement of the intervention process and assist with acceptance and follow through to reach the goals of the interventions. In addition, the goals of any intervention should be meaningful to the families' everyday lives (Cappe et al, 2011; King, Currie, Burtlett, Gilpin, Willoughby, Strachan, Tucker, Baxter, 2005).

This research is important to families as well. Parents may appreciate the feeling that they are not alone in their expectations of QOL issues. There is a degree of normalcy that is often needed (Cappe et al, 2011; King, Zwaigenbaum, King, Baxter, Rosenbaum, Bates, 2006). If parents can also articulate their needs and beliefs about QOL issues, they can offer a reason for the decisions they make as parents of a child with special needs. They can also enlist the specific types of support they deem necessary.

Future Research

Even though this study adds to the literature regarding QOL issues for parents and teachers of children with ASD, there is a need for additional research to determine the reasoning behind the responses of the parents and teachers. Future studies might examine the differences between mothers and fathers with regard to the importance of quality of life as well as the differences related to the degree of severity on the autism spectrum.

Concluding Remarks

Quality of life is influenced by personal and environmental entities and their interactions. Parents and teachers are basic components in the lives of all children but often see children in very different settings. The critical interaction issue for children is the need for collaboration and communication between the parents and teachers. If there is not congruence about the importance of quality of life issues, the goals may be significantly different. This research reveals that parent and teacher viewpoints about which components are truly important, do not always correspond. Hence, it is unlikely that the expectations for QOL, and therefore perceived life-long needs, will be the same.

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