

**Karim Hajhashemi / Nerina J. Caltabiano /
Rebecca Lovisotto**

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Satisfaction in Parents of Children with
Autism Spectrum Disorder**

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Parental Stress, Affective Symptoms and Marital Satisfaction in Parents of Children with Autism Spectrum Disorder

Rebecca Lovisotto

Nerina J. Caltabiano

Discipline of Psychology, College of Healthcare Sciences
James Cook University, Australia.

Karim Hajhashemi

College of Arts, Society and Education
James Cook University, Australia

Abstract

Parents of children with Autism Spectrum Disorder (ASD), a life-long developmental disorder, responded to an online survey considering their stress experience, affective symptoms and marital satisfaction. As these parents sourced different programs for their children, type of program was used to assign parents to different groups in order to consider their stress, affective symptoms and marital satisfaction. The type of programs parents used included the Applied Behaviour Analysis (n=15); Early Intervention Centre (n=13) and no formal program (n=16). Parents of children with ASD in the ABA group reported significantly lower parental stress scores, lower affective symptoms scores and higher marital satisfaction scores compared to the other two groups. These results are suggestive of the beneficial effect that an ABA program can have on the family unit.

Keywords: Parental stress, parental depression, marital satisfaction, Autism Spectrum Disorder, Applied Behaviour Analysis, Early Intervention Centres

1. Introduction

Autism Spectrum Disorder (ASD) is characterised by qualitative impairments in social and communication behaviour, and a restricted range of activities. With the prevalence of ASD on the rise, the impact this disorder has on the family is worthy of investigation particularly as the stay-at-home mum that could have devoted time and effort to care for the child is a less likely occurrence. Management of ASD is regarded as highly crucial in relation to the developmental process of ASD children. Research (Corsello, 2005; Harris & Handleman, 2000) has found that children who are diagnosed as young as two and start a management program at diagnosis, are more likely to gain greater benefits from a program than children diagnosed at later ages. Other research (Grindle, Kovshoff, Hastings, & Remington, 2009; Osborne, McHugh, Saunders, & Reed, 2008; Remington et al., 2007; Roberts et al., 2011) has considered different program types with some giving more positive outcomes than others. In particular, programs based on the principles of Applied Behaviour Analysis (ABA) have shown optimistic results for children with ASD compared to others.

The choices parents make for how they manage their ASD child can have impacts on their personal wellbeing. In this study we focus on those parents who have used an ABA program, and early intervention centre and those that have not considered any formal program. Programs based on ABA are highly intensive and involve up to 40 hours of intervention each week. Many studies (Ben-Itzhak & Zachor, 2007; Najdowski, Gould, Lanagan, & Bishop, 2014; Remington et al., 2007) have indicated that ABA programs efficiently remediate the intellectual, linguistic and adaptive deficits associated with ASD. Early Intervention Centres (EIC) are better viewed as an alternate to day care centres or preschools (McGee, Morrier, & Daly, 1999). They cater for children within a limited age range of four to seven years of age. EIC programs only offer 10 to 15 hours each week. EICs only show an increase in development for children who are 4-5 years old (Luiselli, Cannon, Ellis, & Sisson, 2000). To date research has mainly focused on parental stress and wellbeing of parents who have a child with ASD.

One Australian study that has considered the association between intervention programs and parental variables is the work by Roberts et al. (2011). Their randomised controlled trial did not find group differences in parental stress between ABA interventions and wait-list conditions. Other empirical articles show that parents of ASD children have higher levels of parental stress and higher affective symptoms when compared to parents of typically developing children or children with other disabilities (Brobst, Clopton, & Hendrick, 2009; Dumas, Wolf, Fisman, & Culligan, 1991; Miranda, Tárraga, Fernández, Colomer, & Pastor, 2015). These elevated stress levels have also been reported across cultures. For example, Mori, Ujiie, Smith, and Howlin (2009) reported elevated stress levels in a sample of Japanese parents and Koegel et al. (1992) reported elevated stress levels in a sample of German parents. These stress levels were in comparison to both parents of typically developing children or children with other disabilities (Koegel et al., 1992; Mori et al., 2009).

The increases in parental stress have also been reported despite methodologies or measurement tools used. For example, Koegel et al. (1992) used measurement tools designed for children with disabilities and Dumas et al. (1991) used measurement tools designed for general populations. Both studies concluded with similar results highlighting the increase in parental stress of parents with ASD children.

Nevertheless some studies (i.e., Nachshen, Garcin, & Minnes, 2005; Sharpley, Bitsika, & Efremidis, 1997) have found the contrary. Sharpley, Bitsika and Efremidis (1997) noted that 20 percent of the sample did not perceive or report the situation to be comparably stressful. However, it could be argued that the research failed to accommodate the variance in diagnosis (Nachshen et al., 2005). Mori et al. (2009) found that parents whose child fell on the high end of the ASD spectrum show significantly lower stress levels compared to parents whose child fell on the low end of the spectrum. In brief, parents who reported no increase in parental stress may have had a child who was at the high functioning end of the ASD spectrum. However, despite these findings, the majority of empirical outcomes indicate that parents of ASD children do show an increase in parental stress. In an attempt to explain these increased parental stress levels the Family Adjustment and Adaptation Response Model (FAAR model) can be used (Patterson, 2002).

The FAAR model, which extends from the Family Stress Theory, breaks down increased parental stress into three levels (Patterson & Garwick, 1994). The first level, situational meanings, is the definition the parents construct from the stressful event. For example, when parents are told their child has Autism Spectrum Disorder (stressful event) each member of the family begins a process of constructing meanings as they interact with each other. During this process parents might also search for a cause, which often leads to self-blame (Patterson, 2002). Self-blame or feelings of worthlessness and failure not only increase stress levels, but affective symptoms (Hoppes & Harris, 1990). In addition to searching for a cause, parents also have to refine or develop expectations about who is responsible for managing the illness (Patterson, 2002). This procedure can also contribute to higher levels of stress experienced by family members. In short, the first level of the FAAR model can provide the foundation on how well parents, whose child is diagnosed with ASD, cope with the presented stressful event.

The second level of the FAAR model is family identity and reflects how the family views itself. When a child is diagnosed with ASD, the parents have to change the family routine to accommodate the ongoing needs of the child. This includes changing roles, family routines and rules within the family structure. Ultimately this process can disrupt the family's organisational structure, which may precipitate a crisis as parents may adapt to the situation differently or disagree on the family structural changes. This crisis can put a strain on the couple's relationship that can lead to a family breakdown affecting the couple's marital satisfaction (Patterson, 2002). Some researchers (Bluth, Roberson, Billen, & Sams, 2013; Brobst et al., 2009; Risdal & Singer, 2004; Santamaria, Cuzzocrea, Gugliandolo, & Larcan, 2012) have found that parents with ASD children report lower marital satisfaction compared to parents with typically developing children or children with other disabilities. Low marital satisfaction then contributes to parental stress as a strain develops between finding adequate time for the partner and child, as the child requires more support (Brobst et al., 2009). However, additional research has not confirmed these findings. For instance, Havens (2005) concluded that the challenges posed by an ASD diagnosis strengthened and enriched the couple's relationship. It was further suggested that having a child with ASD only contributed to the relationship negatively if the relationships had existing problems (Taanila, Kokkonen, & Järvelin, 1996). These inconsistent findings could be attributed to the use of different methodologies.

The third level of the FAAR model, family worldview, reflects the parent's orientation toward the world outside of the family. This includes how they interpret reality, what their core assumptions are about their environment, as well as the family beliefs regarding their purpose in life. When a child is diagnosed with ASD a family worldview can often be shattered and full of uncertainty and ambiguity. Parents are often reported to seek emotional support from other parents in similar situations to gain a shared worldview (Patterson, 2002). However, this process can be highly stressful when limited services are available to help manage and provide support or treatment for the child. Research has reported that if treatment programs are hard to access then parents' stress levels are more likely to increase (Grindle et al., 2009). Furthermore, if the program is ineffective then the parents' stress levels are going to escalate more. This concept then can contribute to parents being cynical and having a lack of trust in others, which can lead to a negative family worldview (Patterson, 2002). In brief, if there is a lack of treatment options and if treatment options are ineffective, parents' stress levels are most likely going to rise.

This notion is gaining attention within the literature with emphasis on how different types of programs affect the parents as well as the child. Osborne et al.(2008) noted that parental stress was linked with the developmental process of the child. The study noted that advancement in intellectual, education, adaptive behavioural, and social skills are associated with parental stress (Osborne et al., 2008). In short, if the child's developmental process increases, then the parent's stress levels and affective symptoms should decrease. However, more research is needed here. A study by Grindle and colleagues (2009) reported that some factors in implementing ABA programs were actually stressful. These include difficulties in finding professionally trained ABA therapists, lack of privacy due to the frequency of therapists in the home, and lastly the ongoing task of providing new learning material (Grindle et al., 2009). However, this study included no standardised measures of stress. What is more, a study by Remington et al. (2007) reported no evidence that ABA programs increased parental stress levels over a longitudinal period. In relation to EICs, there is little to no research, in particular within Australia, which has reported the effects that it may have on parents. Due to this, the following research aims to contribute to this new direction of research. The following study aims to identify if there is any differences between parents of children with ASD who are implementing ABA programs and parents whose child is only enrolled in an EIC in relation to parental stress, affective symptoms and marital satisfaction.

It is hypothesised that parents of children with ASD whose child is undergoing an ABA program (ABA group) will report lower parental stress scores compared to parents of children with ASD whose child is only enrolled in an EIC (EIC group) or whose child is not receiving either the ABA or EIC programs (Comparison group). These differences are also hypothesised to extend into affective symptoms and marital satisfaction in that parents of children with ASD in the ABA group will report lower affective symptom scores and higher marital satisfaction scores than parents of children with ASD in the EIC group or the comparison group.

2. Method

2.1 Participants

Table 1 presents the characteristics of the parent participants. A comparable number of parents reported having enrolled their child into either an ABA based program (n=15), an early intervention centre (n=13) or neither the ABA or EIC programs (n=17). Those whose child attended an ABA based program relied mainly on partner support (n=13, 86.7%). Parents whose child attended an early intervention centre mainly relied on an Autism Support Group (n=6, 46.2%) followed by parental support (n=4, 30.8%). For the comparison group the sources of support parents relied on were friends (n=8, 47.1%) followed by partner support (n=7, 41.2%). 60.0 percent (n=9) of parents below 40 years of age implemented an ABA based program, and 53.8 percent (n=7) an early intervention centre. Most of the parents whose children did not attend either an ABA based program or an early intervention centre tended to be in the over 40 age range (n=12, 70.6%). Parents with undergraduate degrees (n=7, 46.7%) tended to implement an ABA based program for their children.

Table 1: Participant characteristics

Item	N	%	
Gender	Male	9	20
	Female	36	80
Age (M = 39.7, SD = 7.5)	20 – 30	3	6.8
	31 – 40	18	40.9
	41 – 50	18	40.9
	51 - 60	5	11.4
Parental education	Junior Secondary	5	11.1
	Senior Secondary	12	26.7
	TAFE	8	17.8
	Tertiary	20	44.4
Marital status	Married	37	82.2
	De facto relationship	4	8.9
	Single parent	4	8.9
Support	Partner	22	48.9
	Parents	6	13.3
	Friends	10	22.2
	Autistic Support Group	7	15.6
Number of children with ASD	One child between 0 – 3 years of age	5	11.1
	One child between 4 – 6 years of age	22	48.9
	One child between 7 – 9 years of age	6	13.3
	One child 10 and over years of age	7	15.6
	Two children 0 – 6 years of age	2	4.4
	Two children 4 – 9 years of age	1	2.2
	Two children 7 and over years of age	1	2.2
Three children 0 -3 and 7 and over years of age	1	2.2	

2.2 Measures

An online survey containing measures to assess parental stress, depression, anxiety, overall stress, marital satisfaction and demographic items was used for the study. The demographic section gathered information on the parents' age, gender, education, relationship status and access to autistic support groups or organisations. In order to keep the survey brief no information was gathered on the child's autism symptom severity or any detailed information on the interventions, the style of the ABA intervention, length of time in the intervention, hours of intervention or teacher-child ratios.

The Parental Stress Scale developed by Berry and Jones (1995) measures parental stress in relation to both positive and negative themes. The positive themes include items reflecting emotional benefits (love, joy, satisfaction, fun) and sense of self-enrichment and personal development. Sample statements include "I find my children enjoyable" or "I am happy in my role as a parent". The negative themes include items reflecting demands on resources such as time, energy, money, and restrictions. Sample statements include "having children leaves little time and flexibility in my life" or "it is difficult to balance different responsibilities because of my children" (Berry & Jones, 1995). The scale consists of 18 items, which are answered using a 5-point Likert scale with 1=strongly disagree to 5=strongly agree. Eight items are reversed scored. Higher scores in the total scale indicate higher levels of parental stress. The scale demonstrated an excellent reliability coefficient α of 0.91 for the total sample. Berry and Jones (1995) reported an alpha of 0.83 for their study. The scale has also shown adequate validity through correlations with the Parental Stress Index, $r(233) = .50, p < .01$ (Berry & Jones, 1995). This scale has been used with other cultural groups such as a Chinese sample with a reported alpha level of .86 (Leung & Tsang, 2009) and a Spanish group with a reported alpha level of .76 (Oronoz, Alonso-Arbiol, & Balluerka, 2007).

The Depression Anxiety Stress Scale (DASS) developed by Lovibond and Lovibond (1995) consists of 42 items with 14 items designed to measure each of the negative emotional states. The stress items include statements such as “I found myself getting upset by quite trivial things” or “I found it hard to wind down”.

Statements measuring anxiety include “I was aware of dryness of my mouth” or “I experienced breathing difficulty”. “I couldn’t seem to experience any positive feeling at all” or “I felt that life was meaningless” are examples of the depression items. Each of the 42 items is measured using a 4-point severity/frequency scale to the extent to which the individual has experienced each state over the past week. High scores within each subscale indicate high levels of depression, anxiety or stress. Each individual scale has shown adequate reliability with a coefficient α of 0.96 for depression, a coefficient α of 0.80 for anxiety, and a coefficient α of 0.91 for stress. These coefficient alpha values are comparable with previously reported coefficient alphas ($\alpha = 0.96, 0.89$ and 0.93 for Depression, Anxiety and Stress, respectively) (Brown, Chorpita, Korotitsch, & Barlow, 1997). Researchers have used the DASS in a number of situations with alpha coefficients ranging from .79 to .96 (Crawford, Cayley, Lovibond, Wilson, & Hartley, 2011; Cunningham, Brown, Brooks, & Page, 2013; Oronoz et al., 2007; Szabó, 2010).

The Kansas Marital Satisfaction Scale (KMSS), developed by Spanier and Cole (1976), was used to measure overall marital satisfaction (Schumm et al., 1986). The scale consists of three items in which the participant responds to a 7-point Likert-scale. The items included reflect satisfaction with the participant’s marriage, partner as a spouse, and the relationship with the partner. High scores of all three items combined signify high levels of marital satisfaction. The scale has also reported adequate reliability with coefficient $\alpha = 0.98$, which is comparable with previously reported coefficient alpha levels $\alpha = 0.93$ (Graham, Diebels, & Barnow, 2011; Schumm, Crock, Likcani, Akagi, & Bosch, 2008).

2.3 Procedure

After having obtained ethical clearance from the home institution, a survey allowing participants to complete online was created using Survey Monkey. The survey included an opening page outlining information about the study and a question asking for consent. Once participants consented to participate in the survey by checking the I agree button, they were directed to the online survey. Autism organisations advertised the survey URL link in their respective newsletters. Participants were also encouraged to pass the link onto other parents of ASD children. All data were downloaded as an SPSS output file for data analysis.

3. Results

The correlation coefficients for the measures, the medians, means, range and standard deviations for the total sample are presented in Table 2. As this study used a quasi-experimental design and the data did not meet the assumption that the variance between groups is equal, non-parametric tests were used to analyse the data. The groups in this study included parents who have their child enrolled into an ABA based program (ABA group), parents who have their child enrolled into an early intervention centre (EIC group) and parents who do not have their child enrolled into neither program (Comparison group).

Table 2: Pearson Correlations between the Measures, Medians, Means, Range and Standard Deviations using the total sample

Measures	1	2	3	4	5
1. Parental Stress Scale	-	.51**	.53**	.35*	-.18
2. DASS: Stress		-	.61**	.67**	-.24
3. DASS: Depression			-	.59**	-.46**
4. DASS: Anxiety				-	-.18
5. Kansas Marital Satisfaction Scale					-
Median	52.00	12.50	5.00	3.00	15.50
Mean	50.62	13.50	9.32	4.52	14.28
Range	25-75	1-31	0-35	0-22	3-21
Standard Deviation	11.63	7.34	9.76	4.50	5.84

Note * $p < .05$, ** $p < .01$

The Kruskal-Wallis test indicated a statistically significant difference ($H=6.47$, $df=2$, $N=45$, $p=.04$, Cohen's $f=0.42$) between the ABA group (Mean Rank= 16.03), the EIC group (Mean Rank= 27.42) and the comparison group (Mean Rank= 25.76) on the Parental Stress Scale.

The Mann-Whitney U then indicated that the ABA group (Mean Rank= 11.20, $n= 15$) had lower parental stress scores than the EIC group (Mean Rank= 18.31, $n=13$), $U= 48.00$, $z= -2.28$, $r = -0.43$, $p=.02$. These differences were also found between the ABA group (Mean Rank= 12.83, $n=15$) and the comparison group (Mean Rank= 19.74, $n=17$), $U= 72.50$, $z= -2.08$, $r= -0.37$, $p= .04$. There were no significant differences between the EIC group and the comparison group.

Within the DASS measures, the Kruskal-Wallis test indicated that there were statistically significant differences for depression ($H = 6.02$, $df=2$, $p=.05$, Cohen's $f=0.40$) and the stress ($H = 5.94$, $df=2$, $p=.05$, Cohen's $f =0.40$) sub-scale scores between the groups. For depression, the mean rank for the ABA group was 15.93, for the EIC group it was 25.38, and for the comparison group it was 26.31. With regards to the stress subscale the mean rank for the ABA group was 16.17, for the EIC group it was 27.38 and for the comparison group it was 24.47. However there were no significant differences for the anxiety sub-scale. A Mann-Whitney U test was followed to investigate where the differences were between the three groups in regards to depression. Results indicated that ABA group's depression (Mean Rank= 11.63, $n= 15$) scores were significantly lower than the EIC group depression scores (Mean Rank= 17.81, $n= 13$), $U=54.50$, $z= -1.99$, $p=.04$. This effect size can be described as "medium" ($r = -0.38$). Differences were also found between the ABA group scores (Mean Rank = 12.30, $n= 15$) and the comparison group scores (Mean Rank = 19.47, $n= 16$), $U= 64.50$, $z= -2.2$, $r= -0.39$, $p=.03$. There were no significant differences between the EIC group and the comparison group. A Mann-Whitney U test also investigated where the differences were between the groups for the stress scale. Results indicated that the ABA group's stress (Mean Rank = 11.00, $n=15$) scores were significantly lower than the EIC group stress (Mean Rank= 18.54, $n= 13$) scores, $U= 45.00$, $z= -2.43$, $p=.01$. This effect size can be described as "medium" ($r= -0.46$). This analysis also concluded with no significant differences between the ABA group and the comparison group and EIC group and the comparison group.

For the Kanas Marital Satisfaction Scale, the Kruskal-Wallis test indicated a statistically significant difference ($H = 8.86$, $df=2$, $p=.01$, Cohen's $f=0.51$) between the ABA group (Mean Rank= 29.63), the EIC group (Mean Rank= 15.31) and the comparison group (Mean Rank= 21.66). The Mann-Whitney U then identified that the ABA group (Mean Rank=18.73, $n=15$) had significantly higher marital satisfaction scores than the EIC group (Mean Rank= 9.62, $n=13$), $U=34.00$, $z= -2.94$, $p=.003$. This effect can be described as "large" ($r= -0.56$). There was no significance found between the ABA group and the comparison group, and the EIC group and the comparison group.

4. Discussion

The hypothesis that differences should occur between parents in the ABA group and parents in the EIC group or comparison group in relation to the selected dependent variables was generally supported. Firstly, parents in the ABA group reported significantly lower stress levels compared to parents in the EIC group and the comparison group. These differences were also found in the specific type of stress: parental stress. These results coincide with the FAAR Model highlighting that having a child diagnosed with ASD increases stress levels within the family unit (Patterson, 2002). These results are also congruent with additional research showing an increase in parental stress levels amongst parents who have a child with ASD (Brobst et al., 2009; Davis & Carter, 2008; Dumas et al., 1991). Moreover, parents who implement different types of early intervention programs show different ranges of stress levels. These differences in stress levels may be attributed to the robust distinctions in effectiveness that the analysed treatments have (Dawson et al., 2010; Roberts et al., 2011). These findings provide a groundwork for the underlying notion that improvements in a child's development may lead to a decrease in parental stress levels (Osborne et al., 2008). However, further research is needed to identify the causal effect of why parents in the ABA group have reported significantly lower stress levels than parents in the EIC group. Future work may want to consider controlling for level of education and age.

The results from this research support the hypothesis that parents in the ABA group should report lower affective symptoms compared to parents in the EIC group or comparison group. Findings showed that the ABA group reported lower levels of depression compared to both the EIC group and the comparison group.

These results coincide with previous research showing that high levels of stress can contribute to more affective symptoms amongst parents with ASD children (Brobst et al., 2009). Furthermore, these outcomes also underline the compelling differences between ABA programs and EICs and the effects that they have on parents' wellbeing. However as this study used a quasi-experimental design, where participants have self-selected themselves into the various groups, no causal statements can be made.

The last dependent variable investigated was marital satisfaction. The hypothesis that parents in the ABA group would report higher levels of marital satisfaction in comparison to the EIC group was supported. Interestingly these findings reflect the conflicting findings surrounding marital satisfaction and ASD. Havens (2005) concluded that the challenges posed by having an ASD child increased marital satisfaction. This notion is supported by the reported marital satisfaction of the ABA group. However, the EIC group reported significantly lower marital satisfaction, which is similar to findings by Risdal and Singer (2004) in that parents with an ASD child reported lower marital satisfaction. These results are also suggested to be a product of the type of treatment that is being implemented for the child. Furthermore, additional analysis showed that parents in the ABA group received the greatest amount of social support from their partner compared to the EIC group. However, these findings need further investigation, as there are many variables besides difficulties with parenting an ASD child that may reflect a decline in marital satisfaction. These findings are also congruent with the FAAR Model emphasising additional factors that are associated with marital satisfaction (Patterson, 2002). In short, these reported results are only highlighting that there is a significant difference between the analysed groups and that type of treatment may be a contributing variable.

In conclusion, the results highlight that there is a significant difference between the ABA group and the EIC group in relation to parental stress, affective symptoms and marital satisfaction. These results are congruent with reported findings by Remington et al. (2007) in that ABA programs do not create increased problems for parents. Furthermore, these results may also coincide with the limitations highlighted in research surrounding EICs as sole treatment (Luiselli et al., 2000; Stahmer, Collings, & Palinkas, 2005). In brief, the findings from this study may provide the groundwork underlying the notion that type of treatment effectiveness may lead to a decrease in parental stress. The non-causal nature of this research begs for a controlled randomized experiment in order to determine conclusively whether the ABA program is efficacious for both the child and the family unit. However, assigning individuals to programs poses an ethical dilemma for researchers.

Future research should consider the following limitations of this study. Firstly, a larger sample size is needed with even proportions of males and females. This would allow investigation into the differences between men and women as they face the challenges of caring for an ASD child. Secondly, due to the nature of this research it was not possible to randomly assign parents into the type of treatment their child was receiving. Thirdly, a cross-sectional design was used which does not allow for the determination of long-term benefits from participating in any one program. A longitudinal study design focusing on both children with ASD and their parents would provide better data to determine which type of program is efficacious and has better outcomes for both children and parents. Other types of variables that would be worthy of investigation but were not included in this study include family size, child development indicators and severity of diagnosis of the child. Severity of diagnosis has been found to contribute to differences in parental stress between parents (Nachshen et al., 2005).

This study has highlighted some significant differences between the ABA group, the EIC group and the comparison group. Quite clearly, the ABA program, for parents at least, appears to be instrumental in producing lower stress and depression scores, and higher marital satisfaction scores for the current sample. Addressing the limitations outlined would strengthen the evidence on the effectiveness of programs thus ensuring parents can make informed choices about the programs they choose for their children.

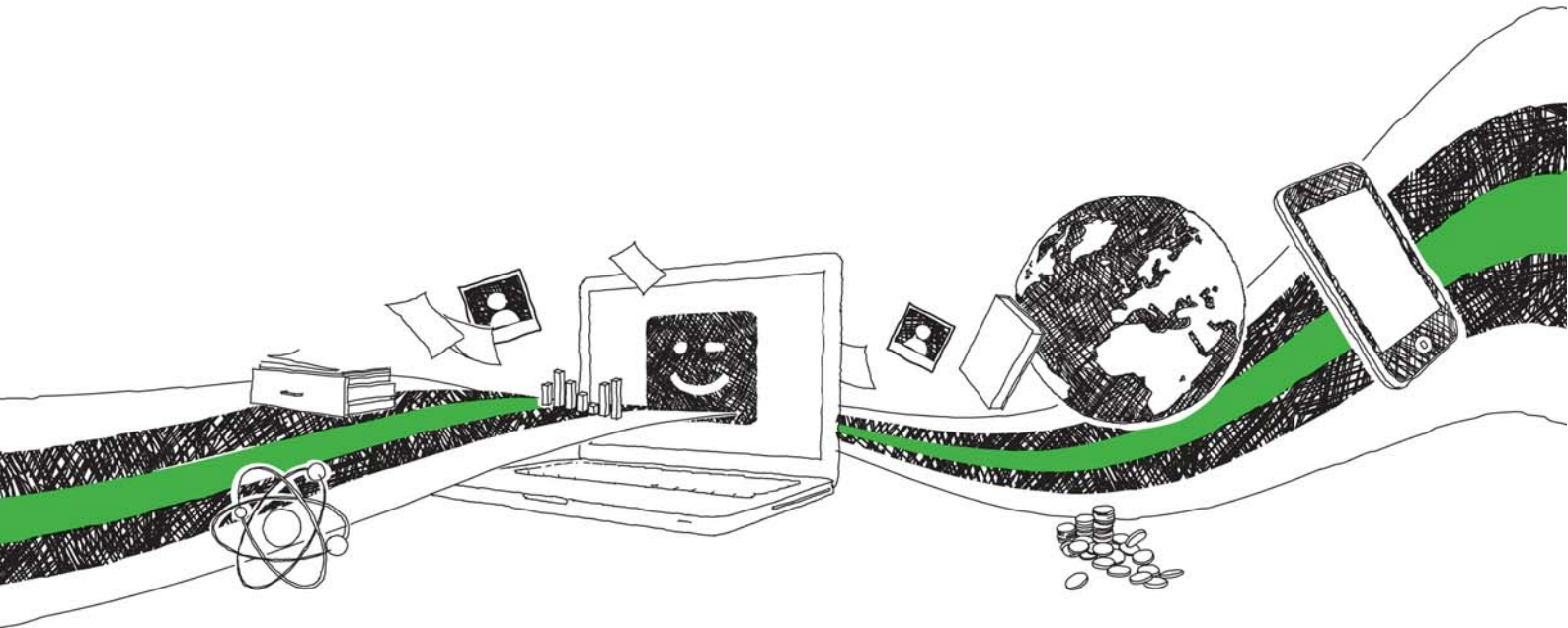
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