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Family Impact of Care and Respite Service: Life Experiences of Mothers of Adult Children with Intellectual Disability and Mental Disorders

Marcia IRAZABAL¹, Crescencia PASTOR², M. Cruz MOLINA³

Abstract

The present study was designed to investigate the impact on families of care as perceived by the main carers (mothers) of adult children with intellectual disability and mental disorders, and to learn about the experiences and opinions concerning the respite service of the participants in the study. The methodological focus was qualitative, based on an exploratory study. Four participants were interviewed in depth. Analysis of the content was based on the dimensions of family impact of care and respite service, and it was carried out with Atlas.ti software. The most relevant results regarding the family impact of care indicate a negative impact upon learning of the disability, giving rise to a situation of family crisis and a concomitant grieving process. Concerning the perception of care the testimony given emphasizes overprotection, mutual dependency, the feeling of overload, and concern for the future, as well as feelings of pleasure and gratitude. Areas shown to be lacking include space for oneself, as well as the emotional, psychological, and physical domains. The respite service is seen to offer relief although it also induces feelings of separation and guilt. The main conclusions highlight; the need for understanding the family and the intellectual disability as complex phenomena, the existence of a double dimension in relation to the impact of care and the respite service as a necessary support. The results of this study may serve as a guide to future research in this area.

Keywords: intellectual disability, mental health, family impact, respite care, qualitative study, families.

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Introduction

In order to carry out social and educational interventions that are both more complete and effective it is necessary to understand the role and the needs of informal carers of adults with intellectual disability (henceforth ID) and associated mental disorders (henceforth MD). There is little in the literature in this regard, which serves to remind us of the need for further research with an array of focuses in order to achieve greater understanding of the family system and ID.

The present study focuses on the impact of the care as experienced and perceived by the main carers, mothers of adults with ID and MD, since, as noted by Krauss, Kim, Greenberg & Seltzer (2003), it is the mothers in most cases who assume the responsibility of caring for people with chronic dependencies. These authors also claim that these carers usually experience mental and physical health problems as well as negatives consequences in their psychological well-being as a result of the stress that the circumstances of providing care give rise to. In addition, research reveals that informal care is carried out in large measure by mothers whose efforts predominate over those of formal care systems (Heller, Caldwell & Factor, 2007; IMSERSO, 2006; Wiener, 2001).

The family is the principal, and most permanent, of support settings, playing the most decisive role in the well-being of the individual with ID (Verdugo, 2004). For this reason it is essential to offer services and support to the family as a whole so as to contribute to an overall improvement in the family's quality of life (Summers *et al.*, 2005; Turnbull, 2003). The network of services and support models on offer, both at the national level in Spain and in the autonomous region of Catalonia, includes respite service (henceforth RS), which is a temporary, short-term support mechanism designed for family members living with people with ID and/or ID and MD. Its aim is to allow family members to continue with their personal, family, and working lives (Respite Program, Provincial Government of Barcelona, 2003). Services of this kind are among the most important agents in helping people lead their lives and in relieving excess burden.

The concept of family burden on the carer has been used in the literature to describe the negative repercussions of informal care of people with ID and MD (Maes, Broekman, Docen & Nauts, 2003; Matthews, Wetson, Baxter, Felce & Kerr, 2008). Nevertheless, other authors, such as Blacher & Baker (2007) and Dykens (2006), maintain that the carer may in fact experience positive effects from caring for his or her child: satisfaction, feelings of pleasure, and the experience of having provided appropriate care. We feel that there should be a favorable, gratifying outlook on the impact that the carer has. This is in line with Hugo Assmann (2002), who recognizes the deep pleasure in learning from experience, be it in the school or in the bosom of the family.

Furthermore, this research aims, on the one hand, to examine the concepts of family and disability based on systems theory and from the perspective of complexity, given that it is developed upon the notion that these two phenomena are complex and require a comprehensive, multidisciplinary approach. But on the other hand it also aims to contribute to the progressive disappearance of the term ‘family burden’ and its replacement by ‘family impact’, which is both more open-ended and inclusive.

Present approaches to intellectual disability: concept and current models

The models in current use are bio-psychosocial, including the WHO’s International Classification of Functioning, Disability and Health, known more commonly as the ICF (WHO, 2001). The present study is based around the current models, as well as linking the phenomena of ID and MD together in the social and familial context in holistic, multidimensional terms. These models establish enabling and support factors as well as those barriers that serve to limit people with disability. We support the idea of Carbonell (2000), who feels that a disability appears when a human being with a certain health condition encounters barriers in his or her surroundings that prevent full and effective participation with others on equal terms. Fundamental to this is the concept of Pantano (2003), who sees the ICF as an integration of the medical and social models-models that, although opposed, achieve a synthesis which, to his thinking, is more coherent for providing understanding of the functioning of the disability, in that it includes three perspectives: biological, individual, and social.

Mental disorders in individuals with intellectual disability

Interest in studying MD added to ID has been on the increase in the past two decades, for two main reasons. First, as indicated by Hemmings (2008) and Salvador-Carulla (2007), is the effort that has been made to recognize and promote the right of people with ID to receive appropriate medical attention. Added to this has been the desire to include these people in the community and to work for the use of community resources on their behalf. Adults with ID are at increased risk of developing mental disorders because of the complex interaction of biological, psychological, social, and familial factors. Something on the order of 20%-40% of people with ID also suffers MD (Bouras, Holt, Day & Dosen, 1999; Cooper, Smiley, Morrison, Williamson & Allan, 2007). Regarding family burden, it is seen to be greater in carers of people with ID and associated MD than in carers of those with ID alone (Bouras, 2004 & Martorell, 2011). Another study by Irazabal (2012) showed how the area of functional disability and participation in society generates both waste and increased family impact in this population.

Family understanding, intellectual disability, and mental health as complex systems

We take as our starting point the idea that the family, disability, and mental health are complex phenomena, and they become more so when one considers the interaction among them. They must be understood in the broadest of terms, and they must be approached using a multidimensional model of intervention. Salvador-Carulla & Bertelli (2008) describe ID as a construct that includes a wide range of conditions deriving from diverse biological, psychological, and social factors.

For families, the experience of having a child with ID or ID and MD has a great impact, often quite painful, and frequently giving rise to moments of crisis with intense repeated feelings of uncertainty, sensations of disorder and lack of balance, and deep pain. This may lead to a feeling of loss, and of the rupture of projects, expectations, and ideals associated with a healthy child. This situation implies a grief that has to be worked through, with the need for accompaniment throughout the different moments of the life cycle of the family nucleus. General systems theory and the life cycle theory of Rolland (2000) are of great utility in understanding the situation of illness or disability that may befall any member of the family. Deinstitutionalization and the shift towards a model of community-based care have led to an increase in the burden assumed by family members in the care of individuals diagnosed with ID and MD (WHO, 2001; Singer & Ryff, 2001). This has also implied an increase in the importance of the role of the carer as a consequence of the informal care provided to family members with chronic illnesses (Fadden, Beddington & Kuipers, 1987; Platt, 1985).

The term family burden has been used by many authors to describe the negative repercussions - physical, psychological, emotional, and financial - of providing care (Tessler & Gamache, 1995). The carers themselves view their personal situation as being highly stressful, and say that the lack of effective strategies and insufficient resources for facing their situations engenders a heightened sense of burden (Lazarus & Folkman, 1984; Maes et al, 2003). However, the carer may also experience positive consequences of the care of the child, such as satisfaction and feelings of pleasure from the care that is offered (Blacher & Baker, 2007; Dykens, 2006). Furthermore, the use of the term 'family burden' shunts aside the positive, gratifying aspects of caring for a family member with ID and/or a mental illness (Blacher & Baker, 2007; Szmukler, Burgess, Herrman, Benson, Colusa, & Boloch, 1996).

The present study was designed to adopt this concept, referring to the family impact of care from a new, wider perspective of the phenomenon under study that includes both the negative and the positive aspects while focusing on the complete view of the care. In addition, this research aims to uncover the usefulness and meaning of RS for the participating families with children attending an occupational center.

Methodology

The methodological design of the present study was qualitative and exploratory, aiming to learn about and understand the subjective, individual experiences of the subjects, and to make sense of these experiences by interpreting the meanings attributed to them by the mothers, as outlined by Denzin & Lincoln (1994).

The main research questions for which responses were sought were the following: Is the impact of the care provided through the various stages of the development of the child entirely negative - that is, one of burden on the mothers? Have they been able to enjoy positive and gratifying experiences that had a significant effect upon them, thereby providing support to fall back on in difficult times? What parts of their lives have the mothers had to abandon in order to care for their children? What other elements, factors, or support would be useful so as to reduce the burden and improve their well-being and quality of life? And has RS been a source of relief for the mothers?

Participants and setting of the study

The inclusion criteria for participation were: Mothers living with their children <18 years of age, with ID and associated MD, who are linked to the center and have attended RS. The participants were the four mothers who fulfilled all of the inclusion criteria. The study was carried out in Barcelona, Spain, at the Occupational Center Sant Jordi of the Parc Sanitari Sant Joan de Déu, a day community center for individuals 18 and older with ID and ID and/or MD.

Analysis of content

An in-depth interview was used to collect data, and for the exploration and interpretation of the data obtained in the interviews the software program ATLAS.ti v6 was used. Two dimensions and their corresponding categories were established for the analysis of the content of the interviews. The first dimension, *family impact of care*, had the following categories: impact of the discovery of the disability of the child; the perception of care; basic care in day-to-day life; leisure and free time activities; areas of reduced activity; formal and informal support and enabling factors. The second dimension, *respite service*, had the following categories: prior process and the decision to attend RS; first visit and successive visits.

Results and Discussion

Family impact of care

To begin, regarding the results of the perception of care by the participating mothers there are various elements that generate a negative impact, but there are also elements that represent a positive impact on care.

The accounts given by the mothers make it clear that they suffered a negative, painful impact upon learning of their children's handicap. This experience undoubtedly caused family crises marked by sadness, pain, disappointment, rage, feelings of guilt, and a sense of loss.

There is a feeling of grief. You have to learn to live with a great deal of anxiety. I lay down and felt as if I was suffocating... (P3, female, 55 years old, April, 2014).

In addition to the impact of the discovery of the handicap of the child, you have to factor in the pain and stress associated with the chronic nature of the disability and its effect on the entire life cycle of the family. As described by Blanca Nunez (2007): "*The evolutionary life cycle of the family suffers greatly with the birth of a child with a disability; in addition to the normal evolutionary crisis you have to add in the effect of this accident, with its characteristic unpredictability and disruption.*" (Nunez, 2007: 60).

The accounts given by the participants speak of concern about the care of their children. The greatest concern shared by all the participants is what will become of their children when they can no longer care for them. As to the most negative experiences, they speak of overprotectiveness and mutual dependence, and of the feeling of overload due to the ongoing need to provide supervision in care:

My son could probably take care of himself well enough, but I do almost everything for him. It's just that I see him as helpless, as a kind of man-boy (P1, female, 57 years old, April, 2014).

I've come to realize that he should be more independent of me, but in fact we are dependent on each other (P3, female, 55 years old, April, 2014).

I know that she is my child, and my responsibility, but I am getting on and it is getting harder and harder to look after her (P2, female, 62 years old, April, 2014).

From these extracts taken from interviews in the study it is clear that there is a negative impact of care, and there is both over protectiveness and mutual dependence in the relationship between mother and child with ID, all of which makes it that much harder for there to be independence and autonomy (Mannoni, 1984). Regarding the feeling of overload, "motherhood is reduced to carrying a loaded backpack, which soon drains you both physically and psychologically,"

according to (Nunez, 2007:195). Additionally, this author adds that the mother may come to see herself as a provider of attention and continuous care—‘sublime love’, as it were—in the process becoming quite attached to her self-image as a mother sacrificing herself for the well-being of her helpless child.

Another aspect that needs to be highlighted is that of the shortcomings that come about in the lives of the participants. First among these is the lack of private space, which was given voice to by all the mothers.

Ever since X was born we haven't gone anywhere without him. We are there just for him (P1, female, 57 years old, April, 2014).

I don't have any free space. I've always looked after others—first my grandmother, then my daughter, and now my mother as well ... (P2, female, 62 years old, April, 2014).

The only thing missing now is to find time for myself (P3, female, 55 years old, April, 2014).

Secondly, the participants speak of having to give up their work and their personal projects because there simply wasn't any time for them:

Obviously I gave up work; my working life came to an end because the doctors told me that I had to be with him and motivate him (P4, female, 52 years old, April, 2014).

Thirdly, it is clear that the psychological, physical, and emotional repercussions are consistent with the results of other studies of the consequences of caring for individuals in a state of dependency.

I didn't feel like singing, or dancing, or laughing, nothing; everything was about X [...] I haven't been able to like myself for a long time. I felt inferior to other people, either because of what I was going through or else my mood was out of whack. [...] I have been living with incredible anxiety for three years. In fact I am taking antidepressants - I have been for two years now - and I'm afraid to come off them because I feel better now (P4, female, 52 years old, April, 2014).

Also, there is a broad consensus among researchers on the repercussions of providing care to people with dependency. As maintained by Krauss, Kim, Greenberg & Seltzer (2003), these families usually experience physical and mental health problems, as well as negative consequences on their psychological well-being as a result of the stress created by the circumstances in which the care is carried out.

It should be noted that from the analysis of the present research there is seen to be a positive impact from the perception of care and from the inter-relations in the nucleus of the family. It is clear that following a period of grieving there is

acceptance and then assimilation of the child's ID, leading to a reorganization of the family system and gratification derived from the care:

I was able to swallow it all, but only little by little, in bits. When I found out about my son's condition, and that there was no chance of a change, I finally accepted things (P1, female, 57 years old, April, 2014).

Then my son X's brother was born, and that changed our lives again, for the better. I'm experiencing motherhood in a different, less obsessive way. So good, I'm relaxing and we are beginning to live again (P3, female, 55 years old, April, 2014).

Additionally, there is another positive dimension to the impact of care, which is the satisfaction related to the feelings of pleasure and gratitude for the help provided—that is, an improvement in the quality of the relationship with the dependent person through the task of providing care. The loving bond is reinforced (Blacher & Baker, 2007; Marks, Lambert & Choi, 2002).

The results of this research also show that there are areas that are broadened, such as the positive aspects deriving from the gratification in caring. By way of example, a mother talks about her experience and the meaning of caring for her child:

I think that all families with a child with disability discover that the parents become better people. Providing care makes you see and understand life in a different way. That has been my experience... There are problems and things that are difficult, but the positive outweighs the negative (P1, female, 57 years old, April, 2014).

Respite service

The experiences of the participants with respect to RS were examined as a process divided into three stages: the earlier process and the decision-making, the first visit, and successive visits. All of the interviewed mothers agreed that RS was a valuable resource for their children. However, these four mothers also spoke of the difficulty in making the decision to send their children to RS; all of them had great reticence to do so at the outset.

Respite service? Great, a place that will provide my child with a little more independence (P3, female, 55 years old, April, 2014).

Respite would be fine, I thought, for me and for my daughter, since she could go there for a time and make friends, and I could get a bit of rest (P4, female, 52 years old, April, 2014).

Yes, yes, the word is fear and none other... it was turning my child around... and it had me going as well...it was like they were going to take him away from me (P1, female, 57 years old, April, 2014).

In regard to the preceding observations, it may be said that the prior ideas of the participants regarding RS are in line with the aims of this service, such as providing assistance of a non-permanent nature to family members living with individuals with ID. This has the goal of helping to reconcile personal, family, and social life and to afford the family some rest (Chou, 2008; FEAPS, 2008). Concerning the *first visit*, there was a common feeling of deep suffering brought on by the separation, along with feelings of guilt and abandonment. One mother described her experience as follows:

Terrible. I took it very badly. [...] I was crying, wondering why I had taken her. I felt very guilty, as if I had abandoned her. I felt remorseful every day (P2, female, 62 years old, April, 2014).

As noted by Blanca Nunez (2007), feelings of guilt plague families with ID throughout the family life cycle. That's why, according to Chadwick (2013), families need support and attention. Work needs to be done to build stronger relations with the families, paying attention to satisfying their needs so that they are better able to confront the challenges that face them.

Finally, regarding *successive visits* to RS, three of the four mothers interviewed used the service more than once, and they agreed that it did indeed provide respite and relief to them. As one of them put it:

When she is in Respite I can breathe ['respirar' in Spanish] (P2, female, 62 years old, April, 2014).

In essence, then, as asserted by Abbeduto, Seltzer, Shattuck, Krauss, Orsmond & Murphy, (2004), a structure of complementary support for families guarantees both the task of providing care and needed rest from it, by reducing the levels of stress, anxiety, and depression experienced by the carers. We must note, however, that despite the satisfaction felt by the families that use RS, they are few. The low level of use of the service is rather paradoxical, given that what it offers is desirable and much needed.

Conclusions

The main conclusions to be drawn from the analysis and interpretation of the results include the view of the family and of ID as complex systems whose understanding is essential to guarantee multidisciplinary intervention. Secondly, the experiences of the participants in relation to the impact of care reveal aspects that are negative and painful, as well as others that are positive and gratifying, meaning that there is a double dimension to the perception of care. And thirdly, RS is shown to be a necessary support to relieve feelings of overload resulting

from the care and attention given by the mothers to their children. From these conclusions we may formulate proposals as to how to make improvements that would provide additional, beneficial support. Among these would be the promotion of social, educational, medical, and psychological actions through community-based services leading to the implementation of inclusive interactive user-family-professional-community programs. The inclusion of families in social and health care plans also needs to be promoted. And support groups for families of people with ID, with or without MD, need to be set up by specialized services. Escort services for one-time support for people in the community with ID and MD need to be set up as well. And, finally, information needs to be disseminated more effectively to encourage the use of respite services, thereby helping to reconcile the family and social lives of the affected individuals.

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