

*Taking care of chronically ill adolescents and their families: doctors, nurses and social workers as a multidisciplinary integrated team or separate professionals? A qualitative investigation **

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Summary. *The progressive diffusion of chronic diseases induces a substantial increase of the number of adolescent patients. Falling ill or being sick during this delicate phase of individual development determines, often, important consequences on the quality of family relationships. Today, multidisciplinary team must respond to physical needs of these teen-ager and their families, but also manage their psychological and social rehabilitation. These teams are composed by operators different for training and professional experience. This research, carried out according to a qualitative paradigm and by narrative methodology, tries an exploratory analysis of different descriptions used by doctors, nurses and social professions telling about family relationship of their patients.*

Keywords: *Adolescence, Family, Chronic disease, Telling, Professions*

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Introduction

A general, gradual spread of chronic diseases has led to a corresponding substantial increase of the number of chronically ill children, including adolescents. The experience of getting sick or being sick during this particularly delicate phase of a person's development can have (in most cases) a significant effect on the quality of family relations.

For every child, family has been always a place where continuity of presence, integrity of education, intimacy and intensity of emotions and spontaneity of relations act as conditions for adults' generativity (Erickson, 1998) and are bases for the child human development (Milani, 1998, Xodo, 2003). It is within his family that a child can learn autonomy and relational competence, both being basic for his life and the development of his sense of responsibility: a family which is able to respond to his needs for protection membership and respect (Maslow, 1943), a family which allows him to develop a sense of "secure internal basis" (Bowlby, 1998), a precondition of his self-confidence. During adolescence a young person must address some unavoidable developmental tasks. These tasks are oriented to the achievement of a personal identity which becomes more and more distinct and original, through a process of emancipation from the parents. By his lived-through experiences, projections and identifications, a young child progressively develops awareness of his being unique and original individual, and there emerges in him a desire for greater personal autonomy gradually, as it must, individual (Erickson, 1998, Petter, 1990, Peretti, 1976).

Parents, however, have to find new ways of interaction, communication and dialogue with a child who is no longer a child and not yet an adult, but on the edge of two definitions. For young children, on the other hand, adults are points of reference, because they are those who set the limits, opposing his individualism. This contrast can cause a conflict between adolescents and adults, but unless it threatens some basic relationship values, conflict can in itself become a vehicle for growth by requiring all parties involved to express responsibility and respect for each other. Only a family founded on dialogue, reciprocity and negotiation can the development of a child's autonomy. Often, however, parents are not able to offer this kind of care to their children: today many parents tend to lose authority in education exposing adolescents to the negative influences of peer group pressure and mass-media culture (Palmonari, 1993, 2001, Petter, 1990, Massa, 1990, Polli Charmet Riva, 1995, Galli, 2001, Mari, 2007, Bertin, Contini, 2004).

In this complex dynamic, the experience of living affected by a chronic illness pervasively intrudes upon a process: diabetes, asthma, dialysis, heart failure, organ transplant (and consequent immune-suppressive therapy) are some of the most common chronic conditions that can afflict teenagers and that may often become factors contributing to further difficulties in intra-family relationships, between parents and adolescents. The literature, although unfortunately limited on these issues, highlights some of the many difficulties which parents of these children have to face this delicate educational adventure. Studies identify and in detail parents' attitudes as being defined by a sense of guilt, anxious overprotection and rewarding permissiveness. These data are already present in historical studies by Anna Freud (1965a, 1965b). Other more recent researches describe a significant correlation between the family's functionality and child's compliance: in this way the quality of familiar intra-relations is able to influence directly the child's quality of life. Incompliance, instead, is often the result of an arbitrary confidence granted by parents to left alone to manage their own diseases but who are not yet fully aware of the consequences of their self-made choices; in other cases, lack of adherence is the result of the adolescent's attitude to risk denial, or a deliberate on his part to prove his right to self-determination (Uzark, 2008; Anderson et al., 1997, 1999, Shapiro, 2002). Other studies describe, however, a high frequency of conflicts between parents/couples, probably due to stress associated with the management of a child-patient: parents are often not able to come to agreement on choices about taking care of the child and his illness (Kurnat, Moore, 1999; Anderson et al., 2002). Finally, studies highlight a strong bond of dependence between parents and adolescents. In contrast with the child's needs for independence and self-determination which are physiological at this age, anguish and sense of guilt lead some parents to express overprotective attitudes towards their sick child. Overprotection may induce adolescents to feel a sense of suffocation, which may lead them to react in an aggressive or violent way. In other cases it is the child who looks for an intensive relationship of care with his parent, as a compensation for the lack of peer friendships. Even in these cases, however, the adolescent's developmental process may abruptly break off with important consequences for his future as an adult (Michaud et al., 2007, Laffel et al., 2003, CintraBuchornDamiao, Marcondes Marques Pinto, 2007).

Today a multidisciplinary team is required to take care of these patients and to meet their therapeutic needs, a team which integrates different skills and which is able to offer support not only to the physical needs of these children, but also to respond to their psychological and social needs, as

recommended by the Ottawa Paper (WHO, 1986). Not only doctors and nurses, but also psychologists, educators and teachers work hard every day to take care of these young people and, even if indirectly, of their families, with the aim of caring for their health – which is defined as a state of subjective well-being, a synergy of physical, psychological and social factors (WHO, 1946). In addition, care professionals act upon the evidence, widely cited in the literature, according to which satisfaction of the vital needs of the child has a significant impact on therapeutic process, as well as limiting possible traumatic outcomes related to living with the illness: this is possible by allowing the child to develop those psychological coping strategies that may help him to face his pathological situation (Aujoulat et al., 2006, Thompson, 2009). However, these professionals have been trained in very different fields of study, aimed at following almost irreconcilable learning targets. Later, in the workplace, care professionals observe and live through similar experiences but it is highly plausible that they perceive the same events in different ways, partly due to their training and partly due to their professional role: doctors are oriented towards clinical-therapeutic targets, nurses to assistant ones, social workers to educational and relational ones. Previous studies recognized that professional training or work experience are able to define an individual's attitude towards reality (Allport, 1976). Attitude is thus capable of significantly influencing a person's perception of reality, and, consequently the quality of his or her choices (Ajzen, Fishbein, 1977). In this sense, professionals' different training, as well as experience, can influence their attitudes with respect to the choices they should make. Based on this assumption it is interesting to assess professionals' attitudes towards the life history of their young patients and their families. Exploration of these attitudes can provide useful clarifications on the quality of the responses that doctors, nurses and social worker are able to give to adolescent patients' needs, not only from a physical point of view, but also from a psychological and social one.

This paper aims to explore and describe doctors', nurses' and social workers' representations of the intra-family relational network belonging to adolescent patients and their families. The hypothesis of this research is that there exist substantial differences in the quality and quantity of the descriptors used by the various professionals when discussing the case-histories of adolescent life observed during the exercise of their professions. Assuming that these indicators are consistent and visible signs of ingrained attitudes (Ricoeur, 1986), this diversity, if confirmed, can give stimulus to discussions about the quality and significance of team work

currently being carried out by the various players in the Italian Pediatric working field.

Research design

Our research has been driven by a qualitative approach, oriented by a phenomenological hermeneutic paradigm (Gadamer, 2004, Ricoeur, 1986, 1950). By analyzing the content of some histories told by the subjects involved, it was possible to describe and understand the verbal expressions used by professionals asked in narrating their patients' histories, and, at the same time, to comprehend the subjective world they describe. Operationally, therefore, the inquiry was carried out by the method of narrative research (Chase, 2000), using semi-structured in-depth interviews (Goode, Hatt, 1952, Silverman, 2008).

Some professionals whose daily work is taking care of chronically ill adolescents (pediatricians, nurses, health educators and teachers assigned to pediatrics departments) were contacted. Professionals who agreed to contribute, being privileged witnesses (Corbetta, 1999) of the existential vicissitudes of many sick children, reconstructed, when asked, the histories of some of their patients, focusing on those children who expressed particular problems in family relationships.

14 professionals were involved, working in different health situations in the Veneto, Italy. As our research require a qualitative approach, the parties involved were not selected according to criteria of representativeness, but rather by our intention to examine a sufficiently broad and varied sample for the object of our investigation (Strauss and Corbin, 1990). For this reason, the health professionals selected belong to different departments and different specializations (basic pediatrics, nephrology, cardiology, and allergy) and different health contexts such a university clinic and some minor hospitals. All interviews were conducted on non-standardized protocol (Bruschi, 1999), in which there are only some issues on which researchers have to focus and freely stimulate the dialogue (Fontana, Frey, 2000). Interviews were conducted during in-service hours and recorded on digital media.

Data collected were analyzed after being transcribed. Each history has been read and re-read, looking for recurring themes. A content analysis was carried out with the support of software (Atlas.ti)¹.

Every expression, term or paraphrase related to the five main categories (families) of investigation has been identified as unit of analysis:

1. couple: all matters relating to the affective bond between mother and father as partners
2. parents: everything related to the affective bond between mother and father as parents
3. adolescent: all relating to the child/patient.
4. mother: everything related to patient's mother as a mother of a chronically ill teenager
5. father, everything related to patient's father as a father of a chronically ill teenager.

Each indicator (quotation) was collected in some 59 categories (codes) differently replicated among the three major types of professionals involved: doctors (identified with an "m."), nurses (id. "n. "), social workers (id. "sw. "). In total the number of codes identified was 136.

Following the coding phase, the data were graphically represented to analyze the intersection of the major categories of professionals and the identified code families. The highlighted networks become useful in identifying the quantitative and qualitative differences characterizing the descriptors used by specific professions. The number of quotations (phrases) binding to each code and their differing frequency distribution add new data relevant to the discussion.

¹ The Atlas.ti is a software which allows to select parts of the text (words, phrases, ...) called quotations, and insert them into some categories (codes) defined by the researcher. Then it is possible to create some networks, as cognitive maps, characterized by the chosen codes interrelated to each other by significant links, chosen by the researcher from the proposals, limited, offered by the program. Networks created are a graphic and significant representations of researchers' interpretations of the expressions told by interviewers.

Search Results

Researchers collected 14 interviews, which contain 32 stories of adolescents' lives: 12 histories told by doctors, 8 by nurses, 8 by social workers. Among these are 6 histories describing some functional families, equally distributed among the different professional categories. All the others, instead, describe dysfunctional families. These data are coherent with the researchers' request that interviewees focus on patients whom they remember as problematic.

Overall, 136 codes were defined, 91 (67%) were positive, 45 (33%) negative. Codes were distributed among the five families identified across the three professions by different variable frequencies. Qualitative and quantitative variations of codes are visible in Table n.1

Tab. 1: Qualitative and quantitative distribution of underlined codes

		Doctors	Nurses	Social Workers
Couple	Positive		Good Cultural level Solidity (2)	
	Negative	Conflict Cultural Deprivation Communication problems Separation (4)	Cultural deprivation Separation (2)	Conflicts Economic Deprivation Separation (3)
Parents	Positive	Saddened Loving Competence Good management of sibling Family good management Balanced Presence Supportive (8)	Authoritative Good management of sibling Competence Transmit security Balanced Presence Protective Supportive (8)	Provide security Presence (2)
	Negative	Anxious Delegating Expose to risks Frightened Overprotective Lying Denying Transmit anxiety (8)	Absence for caring other children Delegating Mistrust Frightened (4)	Anxious Absence Conflicts Overprotection Transmits anxiety (5)
Adolescent	Positive	Acceptance Autonomy (2)	Autonomy Good relationship with operators Good relationship with parents (3)	Focus of parents attentions Good relationship with operators Serene (3)
	Negative	Abandoned Anxious Takes advantage to parents Depressed Dependent Denying Inadequate Bad relationship with father Bad relationship with	Aggressively against operators Aggressively against his mother Anxious Depressed Dependent of his mother Inadequate Denying Seeking for attentions (8)	Abandoned Anxious Closeness Depressed Denying Opposition Rebelling Regression Loneliness (9)

		operators Rebelling (10)		
Mother	Positive	Competent Loving Presence (3)	Presence Supportive (2)	Balanced Presence Supportive (3)
	Negative	Anxious Absence Absent to care other children Accomplice Excluded Overprotective Denying Sense of guilt (8)	Absent to work Absent to care other children Delegating Inadequate Denying Not able to transmit security (6)	Anxious Absence Depressed Mistrust Overprotective Denying Oppressive (7)
Father	Positive	Balanced Presence (2)	Transmit security Presence (2)	Loving Balance Presence (3)
	Negative	Absence Absent to work Mistrust Excluded Expose to risks Inadequate Incompetent Overprotective Oppressive towards his wife Denying (10)	Absence (1)	Absence (1)

Intersecting families and professionals categories it is possible to find some useful evidence for the investigation.

Couple: the first meaning data is the presence in all three types of professionals' descriptors of the code "separation" and in two of them of the code "conflict" (doctors and social workers), indicating that these dynamics are extremely common and underlined by all professionals. Doctors and nurses also share "cultural deprivation", but in social workers it become "economic deprivation", while doctors underline also "communication problems." On the positive side, nurses showed a certain solidity of pair and a good cultural level of the couple. The code with the number of quotations more consistent is "cultural deprivation", which is recorded 4 times, both among doctors and nurses.

Adolescent: codes "anxious", "depressed", "denying" are shared by all three professional categories, "rebelling" and "abandoned" by physicians and social workers, "dependent" and "inadequate" by physicians and nurses. Doctors recorded boy who "takes advantage to parents", "bad relationships with operators" and "... with his father." Nurses "aggression against his mother" and "operators ...", "attention seeking." Social workers "loneliness", "regression", "opposition", "closure".

With regard to the positive codes, doctors and nurses share only "autonomy", doctors emphasize "acceptance" of disease, nurses "good relationship with the staff" and "... with the parents", social workers "good relationship with operators", "serenity" and "to be the center of attention" of the parents.

Codes are more consistent of quotations among medical professionals: "autonomous" (7), "denying" (16), "dependent" (8), "anxious" (5) "takes advantage to parents" (5), "depressed" and "rebellious" (3). For nurses "attention seeking" (5), "dependent", "depressed", "abandoned", "aggressive against their parents" (3). For social workers "denying" (5), "depressed" (6), "anxious" (3).

Parents: codes "frightened" and "delegating" are shared by doctors and nurses, "overprotective", "transmit anxiety", "anxious" by doctors and social workers. Doctors add "expose to risks", "lying", "denying"; nurses: "absence" due to the care of other children, and "mistrust" toward healthcare professionals. Social workers the "conflict" between parents. With regard to the positive codes, doctors and nurses share "balanced", "supportive", "competent", "good management of the siblings" (not sick) and then "present." The presence is also detected by social workers, who share with nurses also "provide security". Among physicians there are also "saddened" and "loving" and "family good management". Nurses underline "authoritative", "protective".

Codes are more consistent for physicians: "denying" (7), "overprotective" (10), "exposes to risks", "anxious" (3); "supportive" (6) and "balanced" (4). For nurses "supportive" and "competent" (4), "balanced" and "presence" (3).

Mother: doctors, nurses and social workers share only "denying", doctors and social workers also "anxious" and "absence". Absence "...due to the care of other children" is registered among doctors and nurses. Doctors add "pervaded by a sense of guilt", "excluded from her husband" in the care of the child, "overprotective", "accomplice" to the child in inadequate management of the disease. Nurses stand describing a mother "delegating" that "cannot transmit security", "inadequate" educationally and "absent for work." Social workers share with the doctors "overprotection". They are characterized by "depressed", "oppressive", "mistrust". With regard to the positive codes, all three categories using descriptors that fall under code "presence", nurses and social workers share a "supportive", doctors are distinguished by "loving" and "adequate" health workers for "balanced".

Codes are linked to the more substantial "accomplice" between mother and child (5) for the doctors, the "presence" for doctors (3), and nurses (3). "overprotection" (3) for social workers.

Father: the only codes shared by all three categories are linked to the "absence" of fathers in the care of the child. Doctors add "incompetence", "overprotection" and "oppression of his wife", "exposure to risk" of the child, "mistrust", "exclusion from child's assistance of his wife", "absence due to work", "educational inadequacy", "denying" of the disease.

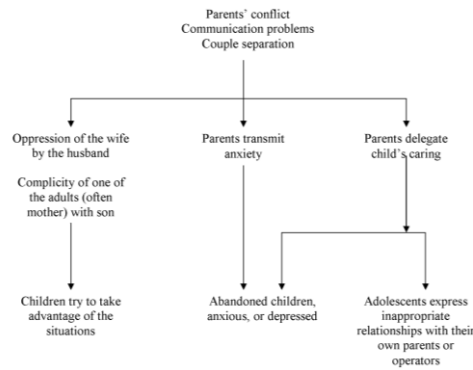
Positive codes: the "presence" is also described by all three professional groups, doctors and social workers add "balanced" nurses "gives security," social workers "loving".

The most consistent codes are "balance" for doctors (6), "overprotection", "exposure to risks", "mistrust", "inadequate" even for doctors (3), the "absence" for nurses (3) and the "balance" for social workers (3).

It is possible to highlight some significant relationships between codes identifying specific differences among the three kinds of professionals. Networks created by linking data highlight intra-family operating models as perceived by the interviewees and as described in the different stories, as shown in the following figures.

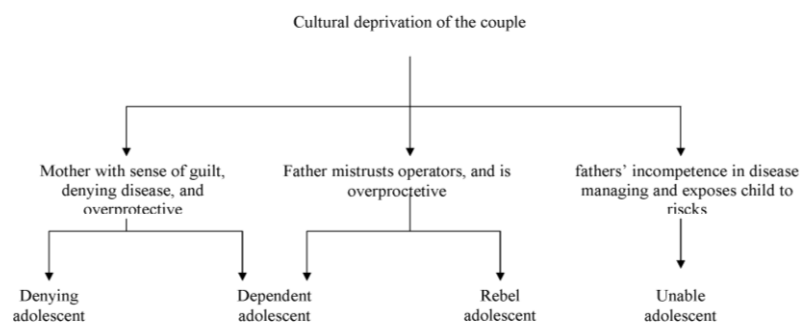
The first network makes apparent the connection between negative codes identifiable in the histories related by doctors (fig. 1): parents' conflicts as well as communication problems are considered components of a real or formal couple separation, which is associated with obstructive behavior between partners, such as oppression of the wife by the husband or complicity of one of the adults with the child (often the mother). In these cases, the child often tries to take advantage of the situation and becomes a party to his mother who indulges him in poor management of his illness. The same internal conflicts between the parents are associated with the father's or mother's tendency to transmit their anxiety to the child, or to delegate his caring. This very delegation is recognized as a possible cause of the child's expression of inappropriate relationships with his own parents or care professionals, or of anxiety and depression related to a feeling of abandonment.

Fig. 1: first network of negative codes underlined by doctors



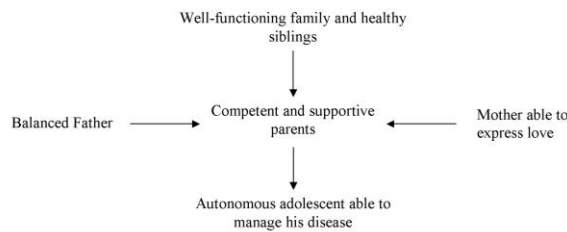
Cultural deprivation of the couple (Fig. 2) is also associated with a sense of guilt felt by mothers, which is considered a cause of the attitude of denying the illness, and consequently of overprotection. On the one hand overprotection is associated with the child's denial of his own illness, as well as his dependency. Yet, according to doctors, cultural deprivation can cause, especially in fathers, attitudes of mistrust in the care-worker's competence, which is also related to overprotection, and which leads the child to be dependent or to rebel. On the other hand, the parents' cultural deprivation may cause the father's incompetence in managing the child's illness, or even lead him to deny its existence. Both factors can expose the child to unnecessary risks or make him develop inadequate management of his illness.

Fig. 2: second network of negative codes underlined in doctors' narratives



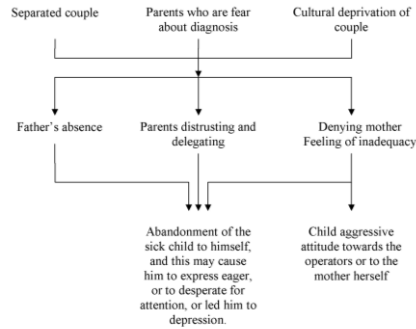
Doctors observe (fig. 3) in a well-functioning family and in healthy siblings the keys to being supportive parents who allow a child's autonomy. A positive and balanced father and a mother able to express her love are the basis of their competence in helping their child to develop an attitude of acceptance of his condition.

Fig. 3: network of positive codes underlined in doctors' narratives



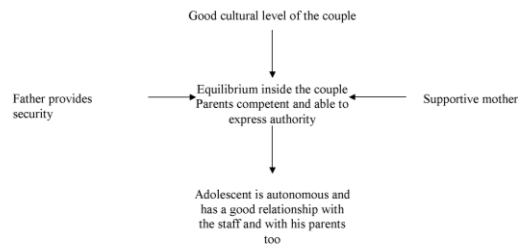
Nurses (fig. 4), however, emphasize above all the parents' tendency to delegate responsibility, especially with the father who is often absent or abandons his family at difficult moments. They define delegation as part of a wider family cultural deprivation or the result of couple's internal problems (such as separation), or simply the result of parents' fears when confronted by the diagnosis. Fear, moreover, is often associated with a family's distrust of doctors' and nurses' competence. This produces the child's denial of the severity of his disease and makes him more fragile and therefore more needing of attention. Delegation sometimes causes the sick child to feel abandoned leading him to express anxiety, or desperately to seek attention, or to become depressed. Cultural deprivation can cause the mother to deny the gravity of the illness, or provoke feelings of being inadequate to educate her child, thus abandoning the child to himself. At the same time these mothers are not able to contain their child's aggressive attitudes towards the care professionals or to the mothers themselves, as was often highlighted by our interviewees.

Fig. 4: network of negative codes underlined by nurses' narratives



Nurses also describe many positive trends (Fig. 5), which come out of a couple's equilibrium and which normally derive from a good cultural level. This can produce parents' expertise and authority leading them to be able to provide confidence, especially fathers, and to be supportive, especially mothers. These children are autonomous and have a good relationship with the staff as well as with their parents.

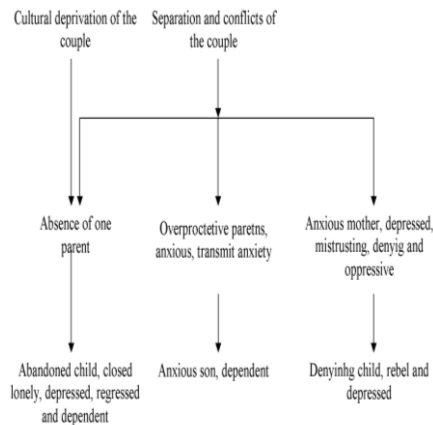
Fig.5 : network of positive codes underlined in nurses' narratives



Social workers also highlight parents' separation (Fig. 6), often associated with the absence of one adult, and underline several cases of cultural deprivation. These situations often induce children to feel alone, to close in on themselves, to regress and become depressed. Conflicts generated by separation often lead parents to become overprotective, and to make their child dependent on them. Other parents, instead, became anxious, tending to transmit their anxiety to their child. An anxious or depressed mother (even if anxious only about her husband's absence after separation) can be oppressive and this attitude may draw out the child's rebelliousness. Most often the mother's depression is associated with a real

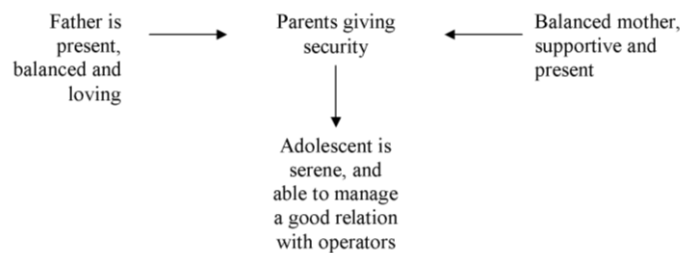
abandonment of her child, who faces his illness alone and becomes himself depressed. The mother's anxiety may also be associated with a distrust of doctors and, in addition, her denial of the illness may lead, by imitation, to the child's demonstration of negative reactions.

Fig. 6: network of negative codes underlined in social workers' narratives



Social workers emphasize (Fig. 7) the importance of a present and balanced father, and a loving, supportive mother: such parents are able to give confidence to their child who becomes calm and capable of a good relationship with care professionals.

Fig. 7: network of positive codes underlined in social workers' narratives



Results discussion

The quantitative distribution of codes across different families and different professional categories shows that fathers are taken into account especially by doctors, who probably tend to refer to the head of the family in communications relating to the therapy. Plausibly, for the same reason, doctors also use many descriptors for the couple understood as parents. On the other hand, nurses and social workers have much lower codes related to the father. All three categories tend to talk mainly about children, parents and mothers, much less about fathers and couples. The bond between mother and father is considered significant as a base of parenting, not as much as a condition of a love relationship, but rather probably because the target for care professionals is the management of the ill child. These data are in contrast with those studies which underline the importance of the quality of the emotional relationship between parents as a significant factor in the management of the child's illness.

Nurses generally tend to be less critical towards parents and couples. In fact, although negative histories are distributed equally among the three categories, nurses are the only ones who record a number of positive codes higher than negative ones. Nurses and social workers tend to talk mainly about mothers, who are more present than fathers in the hospital department and so they may more easily develop a direct relationship with them. Frequently, mothers, nurses and social workers (in this study, all are women) can establish a reciprocal gender affinity. Social workers, unlike other care professionals, tend to be more indulgent towards the child's father; indeed, the related positive codes are greater in number than the negative ones. On the other hand, they often criticize the child's mother.

By using Atlas.ti software it has been possible to create some networks in which identified codes and their possible qualitative interactions are described. As represented in these networks, doctors, nurses and social workers identify as negative elements the couple's cultural or economic deprivation as well as the presence in the family of internal conflicts, which can also lead to formal separation. Therefore all professionals understand that a lack of cultural, social and economic resources, as well as internal conflicts as negative elements for the couple's functionality, have significant effects on the child's life. No positive aspect about couples was found among doctors and social workers whereas nurses especially highlight families' good cultural level and strength of partnership.

The analysis of descriptors used by interviewees speaking about adolescent patients makes apparent more interesting data than previous ones. First, a notably specific psycho-educational language is used by

social workers which distinguish them from other care professionals: in fact they only use codes related to regression and opposition. Nurses instead highlight the children's tendency to be aggressive, both towards health professionals and their parents themselves, whereas doctors probably do not witness these aggressive attitudes, so they simply deduce the existence of a bad relationship between children and parents. Social workers describe a child as rather closed, alone, anxious or regressive, while doctors emphasize the rebellious character, and some children's tendency to take advantage of their parents' conflicts. For doctors, moreover, the child's inadequacy coincides with his lack of compliance. In addition, they emphasize adolescent patients' strong dependence on their parents, which is also noted by social workers. In this sense the quality of descriptors used by the three kinds of care professionals makes their different attitudes clear. While educators and psychologists are concerned about the emotional growth of the child, doctors and nurses are concerned about adherence to therapy and dependence on parents who they are quick to define as unable to manage the situation.

The positive aspects made evident by care professionals confirm this analysis: for doctors and nurses a positive factor is, above all, the autonomy of the child, while, for the other care professionals, it is their calmness and the possibility of being constantly at the center of their parents' attention. The child's parents are, according to doctors, negative when they expose their children to some risks, or when they lie to the doctor about the illness's causes or progress, when they transmit anxiety to their child, when they deny the severity of the disease, when they are overprotective: all elements that negatively affect the diagnostic and therapeutic process. For nurses, however, parents are at fault when they are suspicious, or and when they delegate their child's management. For social workers, it is negative when parents are anxious or when they try to manage every aspect of a child's life in conflict with the child.

In particular, when describing an adolescent patient's mother, doctors refer especially to the sense of guilt that drives her actions, her anxiety which leads to her exclusion by her husband from her child's management, her being overprotective, or complicit with the child. Doctors describe a mother unable effectively to take care of her sick child, a mother who is led by other motives, either personal or shared by the couple. For nurses, instead, the mother is wrong when she delegates her child's management, and does not provide him with a sense of her confidence in him. Social workers identify anxiety and depression as negative elements in the mother, but also her attitude of mistrust and her tendency to oppress her child. The mother's absence from her sick child is justified by most of nurses by citing

job-related motives or the management of siblings, a contingency also recognized by doctors. For social workers instead her absence is unjustified. The positive aspects underlined by care professionals are the mother's presence (a point agreed by all three professional categories) but also the mother's ability to be supportive, balanced and affectionate. As regards the father, consistent with the quantitative results, also from the qualitative point of view, doctors use more numerous and varied descriptors than the other care professionals. Doctors share with the others only the fathers' - which they justify, while the others do not. They add many descriptors defining a father who is unable to handle the situation, who escapes, or, if he fails to escape, acts oppressively against his child or his wife. Alternatively, he completely denies the severity of the illness. Thus doctors see a father who does not accept the situation and avoids his child's pain by running away, in reality or, at least, emotionally. Fathers' positive aspects are highlighted only by social workers with a variety of definitions (affectionate, balanced), while doctors and nurses speak only about fathers' presence and their ability to instill confidence.

Among the codes it is possible to identify some links from which the models of the family's dynamics interpreted by care professionals can be understood. Observing the networks created by the analysis it is evident that even if starting from the same element (separation, conflict, cultural deprivation), the three types of professionals when relating the life histories focus their attentions on different aspects: for doctors they are mainly anxious about parents transmitting anxiety or who are pervaded by feelings of guilt, or who are incompetent; factors cause overprotection and distrust. In cases significant consequences affect the child: he often develops a state of dependence and lack of autonomy preventing him from accepting and managing his illness. Nurses instead highlight the tendency of parents to delegate their care-responsibility, which is associated with a lack of control over the child who therefore often rebels or has reactions of aggression towards staff, especially the nurses who care for him on a day-to-day basis. Finally, social workers emphasize especially the detrimental effects of emotional and psychological imbalances in children whom they describe as anxious, depressed, regressed, and closed-in on themselves. Only by the analysis of the histories told by nurses it is possible to create a positive network, as they appear substantially more magnanimous and generous, less critical towards parents whom they perceive as able to let children develop attitudes of independence and above all able to collaborate with health personnel. In fact, they are the only care professionals who explicitly indicate as one of the causes of parents' inadequacy the fear arising when confronted by the diagnosis.

In short, doctors and nurses reveal a greater ability in describing and analyzing the different situations. Doctors, however, maintain a strong critical attitude, especially against a parent-child relationship that they consider harmful, as they very often critically judge parents who are unable to handle the situation, and focus heavily on the child's ability to be the self-manager of his illness. However, nurses are a little more generous in their judgments and are less critical especially referring to the mothers. On the other hand, these professionals are particularly concerned about the tendency of parents to delegate the care of their children having a direct impact on their work routine. Social workers instead appear more capable of a detailed analysis in terms of emotional and psychological aspects, but they seem sometimes to overlook of compliance, which is very important in these life histories.

Conclusions

From the data we have collected in our research, we can say that while doctors have more tools than nurses to understand and describe the various trends that they see in their patients' histories, they often are unable to look beyond the therapeutic management of chronic illness: even if, with some differences, their narratives are focused on compliance and the factors that can alter it, or on obstacles that they have to face in their daily work. Social workers are focused instead on aspects concerning the child's development and well-being and they are able to grasp the deep yet delicate dynamics of the parent-child relationship. But in their narratives little attention is given to the necessity of supporting the patient's compliance. The results of this study (although limited because of the small number of significant professionals involved, and from which therefore it would be unwise of us to extrapolate generalizations) may offer suggestions particularly useful to confirm our hypothesis: they appear in fact still significant. This suggests that, in many cases, team work is more formal than actual. The health sector is an area of professional action in which different skills (clinical treatment, care and educational relationships) must face up to and integrate with each other. Many authors have underlined the significance of such integration (Binetti, Tartaglino, 2000, Landry, 2000, Giacomelli, Bacherini, 2006, Bertolini, 1994 Tramma, 2003, Canevaro, 2004). Doctors and nurses have to manage therapeutic care combined with educational objectives; psychologists, educators and teachers are required to gain greater awareness and knowledge of the different illnesses that afflict their patients. Nevertheless, as is clear from our study, such an integration of skills is still

far from being reality. Manifold are the reasons that may explain this difficulty. First, the lack of space and time for the meetings, briefings and debriefings which would allow care professionals to discuss and share objectives and targets. Care professionals are instead distracted by the frenetic rhythm of work and the lack of both of economic and human resources. Secondly, an important role is played by the different levels of influence over the decision-making power held by the different professions and sub-professions in a complex organization such as hospital (Gross, Etzioni, 1985): psychologists, teachers and educators have to struggle to find achieve autonomy and a negotiation position with the doctors. This is due to the fact that theirs is a shorter professional history, which actually weakens their social identity, combined with a lower estimation of their knowledge and their skills, coherent with the need to customize any care-relationships.

In conclusion, to be effective, taking care of patients in childhood and even more in should be the result of a synergy of purposes and objectives and an exchange of observations among different care professionals: this is the only way in which the limits of each could be filled by the expertise of the other. However, given the current situation it is necessary to work through training and research in the development of the caring professions, so that they become more recognizable, autonomous and acquire more balanced negotiating powers. Moreover, it is necessary to change medical and nursing education in a humanistic direction; an unavoidable requirement for the creation of effective and integrated teamwork. Above all, it would seem that the situation requires a diffusion of post-graduate training paths (PhD, Masters, higher education courses, etc.) dedicated to offer educators, teachers and psychologists the expertise they need to meet adolescent patients' vital needs and to care for their families as well, but also the relational skills and planning abilities required in team work. Offering such educational possibilities is extremely rare in the current Italian scene. A wider competence, more scientifically founded rather than on imitation of older colleagues, would allow other care professionals to be perceived as valuable by doctors and nurses. These latter, on the other hand, should enrich their own scientific training with a series of humanistic studies to make them more aware of the complexity of the lived experiences and psychological dynamics that illnesses can trigger in their patients. This can be achieved thanks, for example, to narrative medicine, which aims, even for diagnostic purposes, to stimulate, listen to and understand the narratives of patients about their experiences of illness (Bert, 2007, Good, 2006 d). Another strategy can be the so-called Medical Humanities: the inclusion in training programs for graduates in medicine

and surgery of elements chosen from the liberal arts, cultural creations (poetry, novels, music, paintings, etc) in which man has given form and expression to his experience of pain and suffering (Greaven Evans, 2000, Donohoe, Danielson, 2004). It is certainly a process that will take a long time and it will be slow, but, we believe, it is inevitable.

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