FONDAZIONE ISTUD

C.R.Es.C.E.R.E.

"Creating through stories of experiences of care for GH Deficiency the Empowerment toward the Excellence"

Qualitative Consensus meeting on good communication practices in Growth Hormone Deficiency between families and health care teams.

February 25th 2016

Milan, ISTUD Foundation

Results

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Summary

Introduction: the Consensus

The term “consensus” comes from the Latin “Cum-séntire”, which means to feel together, to agree. The methodology of the consent building is a decisional process based on all the stakeholders’ active listening, with the aim to individuate the whole group’s preference. It is not only a way to give voice to the majority of participants, but it is also a way to solve or reduce the minority’s objection, to reach the most shared decision as possible.

The methodology of consensus aims to move from the basic logic of vote, to that of the deliberation, through both rational and emotional arguments (persuasion), to limit personal interests and value the collective one.

This concept comes from the need to reach an agreement starting from different positions, which can contribute at the end of the process to achieve a high degree of agreement, or even unanimously consensus.

The methodology of building of a consensus is based on the theoretical principles of deliberative democracy used in governance models, project management, conflict negotiation, decision making and team building. This new way of sharing of a modality, based on the real context, can contribute to the development of a "common feeling" that can generate greater awareness and appropriateness in the performance of activities, foster creation of a network between all the stakeholders, facilitate the creation of a peaceful climate of work and thus to strengthen the sense of belonging.

This process is particularly important in a broader systemic view, because it can extend the harmonization of practices among several structures, regions or countries. The consensus process can facilitate the emerging of "fresh" and less conditioned ideas. This transfer of experience, ideas and expertise can contribute to the development of a shared working mode, avoiding to set up too standardized procedures, to respect the singular values, and at the same time eliminating the inhomogeneity, harmonizing procedures.

In many healthcare organizations, the consensus has reached mainly through a top-down approach, in which decisions are drown by a small group of professionals who do not take account of all the stakeholders. Through a shared activity of identification and analysis of the critical elements, building of the possible correction factors, selection of indicators to evaluate the results, it is possible to reach the consent.

Objectives

The present activity intends to apply the methodology of the Consensus meeting to the context of the pathway for GHD, basing on the results of the CRESCERE project, to individuate and share a plan for the improvement of the communication between health care teams and families, and their adherence to therapy during the pathway for GHD.

The resulting recommendations will represent a concrete instrument to change the relationship from a top down to a bottom up dimension, moving from the concept of “compliance” to therapy, to “adherence”, up to a real “concordance”, which is the best condition to carry on a successful and long term relation of care.

The main results of the CRESCERE project

The project of Narrative Medicine “Creating through stories of experiences of care for GH Deficiency the Empowerment toward the Excellence" was dedicated to children and young people with Growth Hormone Deficiency, their families and health care providers, through the collection of their stories. By means of the narration tool, this work aimed to implement a rigorous process of listening and comprehension of the true meaning of the therapeutic pathway and its daily implications, on a social, family, as well as clinical level.

11 Italian centres expert in the care for growth hormone deficiency have been involved in the project, representing the whole national territory (North, Central and South Italy), so thus to get a complete overview of the experience of healthcare pathways.

They collected a total of **181 stories** divided as follows:

- 67 stories from children and adolescents with GH deficiency (divided into two groups based on age: 8-12 years and 13-17 years);
- 72 stories from their parents;
- 7 stories from their brothers and sisters;
- 18 stories of their health care professionals, more 17 their parallel charts.

The results from the analysis of stories are collected in an exhaustive report available on the website http://www.medicinanarrativa.eu/progetti/crescere.

The issue of the **relationship between families and health care teams** emerges across all the collected stories.

Children need to be reassured by their cares and at the centre of the medical visits, especially at the beginning of the pathway, when they have to **accept therapy**. Adolescents, in their narratives, express the recurring theme of **impatience against a therapy that involves a daily and increasingly heavier commitment, together with a feeling of not-engagement** toward a relationship of care in which they feel passive subjects; they seem to live therapy and pathway as it was imposed by their parents and physicians. In some cases this impatience leads to a real rebellion towards the treatment, with the risk of fall-out from the therapeutic project.

The demand for support, however, also comes from their parents, for whom it is difficult to support their children' motivation for a long time. They report the increasing their kids rebellion toward therapy. A good communication between health care team and families can **foster these difficult phases of discouragement and make adolescents more responsible for their pathway**. Furthermore, they express the **concern about side effects of the therapy**. They decide to start a treatment for which they know the results, but not the possible future consequences, and ask for more reassurances, as demonstrated by the 67% of parents who tell their worries about side effects. Also parents, like their children, need to be **constantly reassured**.

Therefore, the communication between health care teams and families is a very important element in pathways for GHD to follow and monitor the adherence to therapy and its results. Stories give health care professionals concrete indications to consider all the different points of view and improve care management for GHD and the quality of life of small children eager to grow.

Contents of the Consensus

The Consensus day foresaw an alternation between plenary and working groups sessions.

In the first **plenary session**, the main results of the CRESCERE project have been illustrated, together with the developments of the research, represented by the publication of the narratives and the scientific paper published on Future Medicine. Later, the objectives of the day were shared, with an expert insight into the topic of the care of adolescents who follow pathways for GHD. Lastly, information on the methodology of consensus and working group were provided.

Three working groups have been formed, on the basis of the participants' professionalism and represented roles. Each group, in fact, was composed so thus to maintain the maximum possible representativeness in terms of the roles in the process of care – health care professional, association, family member -, in the specific professional roles - doctor with function of coordination, doctor without function of coordination, nurse, psychologist and other professional – in the geographical origin and the facility of belonging. In this way, the exchange of experiences, good practices and new ideas has been facilitated.

The groups worked on three specific macro-themes related to the theme of communication in the course of treatment for GHD, respectively focusing on **communication addressed to children with GHD, adolescents with GHD and their parents**.

Provided materials

- A summary of the survey report;

- A selection of narratives collected from the CRESCERE project and representative of the three involved points of view - children/teenagers with GHD, their parents and care provider;

- Operating cards to be used in working groups;

- The scientific article published on Future Medicine.

***Working groups phases**:*

1 - Phase of knowledge (self-diagnosis)

• Presentation of the group members.

• Sharing of the different experiences in the pathway for GHD and relationship of care.

• Identification of good practices and critical issues related to the communication topic.

• Identification of priorities and areas of intervention, as in the following format:

PRIORITIES – POSSIBLE ACTIONS OF IMPROVEMENT – WHO TO INVOLVE.

2 - Phase of discussion

• Selection of the priorities for the improvement of the quality of communication in the course of treatment for GHD.

• Formulation of concrete actions to improve each of the identified aspects.

• Analysis of the pros and cons.

• Short and long-term expected benefits.

• Identification/selection of methods and tools to be used.

3 - Phase of the proposal

• Collection of observations

• Formulation of the proposal of each group to share in plenary

Plenary session

- Presentation of the proposals of each working group.
- Collection of observations.
- Open dialogue towards consensus.
- Collection of the contributions from all participants.

The results of the Consensus

Participants

- *Giulia Anzilotti,* psychologist at Meyer Children's Hospital, Department of Endocrinology, Florence;
- *Tommaso Aversa*, paediatrician endocrinologist at Gaetano Martino Polyclinic, Department of Endocrinology, Messina;
- *Isabella Catapano*, reference member of AFaDOC, Milan;
- *Piernicola Garofalo*, paediatrician endocrinologist at Cervello Hospital, Department of Endocrinology, Palermo;
- *Laura Guazzarotti*, paediatrician endocrinologist at Luigi Sacco Hospital, Department of Auxology and Paediatric Endocrinology, Milan;
- *Monica Guerra*, reference member of AFaDOC, Venice;
- *Laura Mazzanti*, paediatrician endocrinologist at Sant'Orsola Malpighi Polyclinic, Department of Auxology, Bologna;
- *Annunziata Officioso*, psychologist at Federico The Second University, Department of Paediatric Endocrinolgy, Naples;
- *Maria Parpagnoli*, paediatrician endocrinologist at Meyer Children's Hospital, Department of Endocrinology, Florence;
- *Sabrina Pilia*, paediatrician endocrinologist at Microcitemico Hospital, Department of Endocrinology, Cagliari;
- *Cinzia Sacchetti*, president at AFaDOC, Verona.

Facilitators:

- *Maria Giulia Marini*, director at Health Care and Wellbeing Area of ISTUD Foundation;
- *Luigi Reale*, project coordinator at Health Care and Wellbeing Area of ISTUD Foundation;
- *Paola Chesi,* researcher at Health Care and Wellbeing Area of ISTUD Foundation;
- *Alessandra Fiorencis*, researcher at Health Care and Wellbeing Area of ISTUD Foundation.

Plenary session

The first part of the day was dedicated to a moment of sharing of the main results of the CRESCERE project and its development, as the basis from which to identify the priorities emerged from the collected stories.

Looking back over the objectives of the project before its start, in 2013, it has been shared how the expectations of getting the national scenario of the experience of care for GHD have been met. The narratives collected have, in fact, offered a **completed overview of the care for GHD**:

from the child's point of view, who describes the pathway contextualized in school, family and social life; from the parents' point of view, who express their satisfaction but also their anxieties; from the practitioners' perspective, who testimony their great motivation and dedication to this care service, despite the many years of profession and the more and more challenging work conditions.

Communication is the topic which crosses all these stories, because every experience of care and treatment is strongly linked to the quality of communication and relationship. A good communication can make the difference not only in the living with GHD and therapy, but also in the outcomes of the therapeutic project, which usually is long and tiring and needs a constant support.

In this plenary session a specific focus on the **adolescents**' experience of care was carried out, since it represents the main issue emerged from the narratives. Also health care professionals, in fact, reveal to perceive in their daily practice the risk of lack of adherence to therapy from teenagers, who after having suffering the care for many years, sometimes can express their rebellion. The debate is focused on the theme of their involvement from the decision-making process: usually parents decide to follow the cure in face of their son/daughter, with the mediation of the health care professional of reference, but teenagers are excluded from this decision; nevertheless, they can already be considered autonomous and ready to detach from their parents – of course making the necessary differentiations within the group of kids, since they can differ in many variables. In the collected stories, and sometimes even during the visits, it is possible to catch the adolescents' requests and signals which it is important to recognize, decode and welcome. Adolescents judge their parents and their health care providers, and are able to decide which paths to follow. Therefore, the relationship of care is not made up of two entities - the doctor and the parent - but three points of view, because the teenager is an integral part of this caring relationship. The health care professional's effort is to move from the central position of the relationship the family, to put at the center the kid, so thus he/she becomes the first recipients of the communication with the health care team. Among the aspects to be considered, there is the awareness that adolescents have a different experience of the disease from children, since it reflects a different concept of the body; the slowing down in growth condition can cause a traumatic vision of their body. The repercussions can be a sense of inferiority, aggression, closure toward the others, even if these feelings are not openly manifested. The communication with adolescents with GHD, therefore, should have the aim to enhance their active participation in the whole process of care, listening to their voice and their needs, and speaking to them in a clear and "adult" way, without using a "childish" language.

Working groups session

Group on communication toward children with GHD

Participants:

- *Laura Guazzarotti*, paediatrician endocrinologist at Luigi Sacco Hospital, Department of Auxology and Paediatric Endocrinology, Milan;
- *Maria Parpagnoli*, paediatrician endocrinologist at Meyer Children's Hospital, Department of Endocrinology, Florence;
- *Monica Guerra*, reference member of AFaDOC, Venice.

Facilitatrici: *Paola Chesi and Alessandra Fiorencis*, researchers at Health Care and Wellbeing Area of ISTUD Foundation.

The communication addressed to children with GHD cannot be separated by the relationship with their parents, since the acceptance of their child's pathway and therapeutic project is at the basis of the care. Sometimes the presence of parents is limited to the mother, who can be the only to manage the care in the family, sometimes the whole family is involved, when the father is a very present figure.

The first element that the health care professional must consider about children with GHD is their **fear**, a very present feeling at the beginning of the pathway, both during the medical visits and starting the therapy. The care setting is the first aspect which can be improved to welcome children in cured and reassuring **waiting rooms**, able to allow, through games and other devices, the interaction among the young patients, even with different disease conditions. Although the waiting room is a place which health care professionals cannot see and they don't know exactly what happens there, they recognize the importance of this place, considering the time spent by children in this environment before finishing all the visits. To confirm this consideration, in the children with GHD' narratives collected within the CRESCERE project, the waiting rooms are frequently mentioned and sometimes described as part of the medical visits, since for them the visit is represented by the entire morning spent in the hospital, including the waiting times. Being in a welcoming environment in which to play, meet other children, enjoy special initiatives such as clown therapy or other possible activities managed by an association, allows children to calm down and feel safe, in spite of feeling "sick" and ghettoized. This attention to the setting of care is the first way to interact at visits with quieter and more open children.

At the first meeting with the child, it is also important the moment of the doctor and care team's presentation, so thus the little patient could know since the beginning the name of the referring physician and why and how they will take care of her/him.

An appropriate **language** can contribute to limit the child's fear of the injection and the idea of being sick, but at the same time words have not to be too childish, since children, even those little, may feel teased. The slowing down of their growth can be explained through a clear language and examples, avoiding to hide the situation but simply presenting it as a temporary condition, something lacking at the moment. This communication can be joined to an open appreciation of all the other aspects of the development which are fine, even with compliments that can gratify children and transmit from the beginning the concept of global growth, not only related to physical stature. The therapy can be presented as the solution to retake growth, but without focusing too much on physical appearance, to avoid that the child could identify himself/herself with the condition of slow growth.

There are strategic tips that can help children to cope better with therapy, such as the possibility to choose **one day a week free from the injection**. This opportunity to reduce the frequency of therapy from 7 to 6 days a week, in fact, can have a positive effect on young patients, who are stimulated to better effort the nightly treatment with the idea of a free evening (sometimes called "the pajama party"). Still, it is possible to give patients practical suggestions on how to reduce their pain during injection (location, small tricks).

A second important issue is the communication to monitor, support and stimulate the children's **autonomy and empowerment on the care**, since their early age. There are two different age groups to be considered. In the case of children who begin treatment at 8-9 years, the training to therapy can be addressed directly to them, showing the kit with all the necessary tools almost as if it was a game, maybe also putting inside a small gift or game that makes it more acceptable in their eyes. In cases of children who start treatment earlier and whose therapy management is relegated to parents, they can be invited to **allow children's gradually participation**; for example, child could choose where to get the shot, or learn how to prepare everything before injection. This way can be considered reassuring both for parents and children, because they are gradually prepared to the detachment from family. The physician of reference's task is to suggest this solution, monitor it and support families in case of difficulties. In situations of particular parents' difficulty to reduce their control on treatment, or excessive dependence of the older child to parents, the process of fostering to autonomy can be more specifically followed from a psychotherapist, or a local association of reference that can help parents to feel more reassured; also the peer counseling from other parents who have faced the same pathway may be very useful to those mothers and fathers.

During all these phases, the direct relationship with children is always important, talking and listening to them. For example, the physician can make patient understand that the injection is less painful if managed independently. On the other side, listen to their direct indications allows to find how to improve the delivery of therapy, because they are the first to experience it and to understand how to reduce pain, giving them, at the same time, a more and more active role.

Finally, there are positive experiences of children with other chronic conditions' engagement, such as diabetes, which can be considered best practices. For examples, the **organization of educational and friendly initiatives addressed to children** can represent important opportunities for comparison, leisure and acquisition of autonomy from parents.

In addition to these two main issues – children with GHD' fear and autonomy - other concrete actions could be helpful for health care professionals in improving their communication with children.

The **communication of the diagnosis** is a fundamental moment of the pathway because, if it is not carried out with delicacy and clarity, can affect the relationship of care, the children and their families' living with the disease, till the adherence to therapy . The most appropriate management of this phase is through two steps: the first communication of the GHD diagnosis should be addressed only to children's parents, so thus to give them time to express their emotions, doubts, and accept the situation. Only later, when parents will be reassured and "emotionally competent", the health care professional can support them in direct communication with their children.

To improve the quality of care services, the identification of a **tutor of reference**, represented by a paediatric endocrinologist who will follow the same family during the whole course of treatment, allows patients and their parents not to feel disoriented by the change of health care professionals. Another organizational element which can help to improve the communication with children is the temporal **separation of the moment of blood sample from the monitoring visit**; the fear of the exam, in fact, may stiffen children and take them to be tense and closed during the monitoring visit, which instead can represent a nice moment to verify the results. This solution has been already applied in some centres of care, leading to good results. From the health care professional's point of view, finally, having the possibility **to manage in a more flexibly way the timing of visits** is important, to follow in the right way children with GHD, who usually make monitoring visits with a lower frequency compared to other chronic conditions, and for the peculiarities of the therapy they may need longer times at disposal. The differentiation in the visiting times between children with GHD and with other diseases could be the answer.

The following table represents the identified actions to improve the communication between health care professionals and children with GHD – *Table 1*

Theme	Action	How	Who
FEAR of medical visits	Improving SETTING OF CARE to create protective and aggregating environments.	Physical improving of the waiting rooms, well-finished and with games that can allow interactions among children.	Health care managers Associations, like AFaDOC Clown therapy associations
	Presentation of the care team at the first visit.		Care team
FEAR of therapy	Adequate LANGUAGE	Avoid a too childish language, not to hide or deny the condition of GHD. At the same time, avoid an excessive focus on physical stature, but convey a concept of global growth, not only physical, to diminish the importance of stature and value the other present	Care team

		elements of their development and of their lives, even with compliments. The stature is only one missing aspect. Use examples.	
	Strategic tips to live better therapy	Illustrate the possibility of a day off from therapy, which can have positive effects on the child's experience, more stimulated in his/her effort knowing to have at disposal a day off after injection ("Pajama party night"). Tips on how to suffer less pain (eg. "The pain can diminish if you make the injection by yourself").	Care team
AUTONOMY AND RESPONSABILITY to care	TRAINING	When possible (with children who begin treatment at 8-9 years) training them directly from the beginning, giving them the kit with all the tools, personalized with a gift, like a game to take care of.	Nurses
	GRADUALITY	In the case of children who start therapy earlier, allow their gradual participation in the management of the care. Eg. Free choice of where to take the injection, autonomous preparation of the needle ...	Care team monitoring Parents
	Pain reduction and reassurance	Listen to children's indication on where and how therapy is less painful.	Care team monitoring Parents
	Specific support in cases of excessive child's dependence from parents	Support from psychologists, associations and peer counseling for excessively present parents in managing their children's therapy, who have troubles in reducing their control and give children autonomy, even with their growing age.	Psychologists Associations like AFaDOC Groups of parents who have already experienced GHD.
	Sharing experiences	Training and educational initiatives addressed to children, enjoying occasions for sharing their experience with others peers.	Associations like AFaDOC
	Tutor of reference	Maintain the same physician	Paediatric

Improving services of care		of reference, who follows families all over the pathway.	Endocrinologist Health Care management
	Separation of the moment of blood sample from the monitoring visit	Allow children to get quiet to monitoring visit, in order to be more open toward the physician.	Health Care management
	Differentiated timing of visit	Possibility to manage in a flexible way the medical visits, on the basis of the specific patient's condition. Distinction between children with GHD, who require more time, and those with other chronic conditions such as diabetes, who follow more frequent visits. Further distinction based on specific treatment phases: the first visits are the longest.	Health Care management Care team
Communication of diagnosis	Gradual process: parents' acceptance first	The first communication of diagnosis has to be addressed to parents, to let them to express themselves, reassure them and, when they will be emotionally competent, communicate the diagnosis to their child.	Care team Parents

Group on communication toward adolescents with GHD

Participants:

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Facilitator: *Luigi Reale*, project coordinator at Health Care and Wellbeing Area of ISTUD Foundation.

The communication addressed to adolescents with GHD is complex because it requires health care professionals to adapt to the many facets of the teenagers, who change very quickly and are different from each other.

The first issue to be considered in a relationship with adolescents is their **impatience**, as revealed by their own narratives collected within the CRESCERE project. Even for them, as well as for children, the beginning of the visits is represented by the **waiting room**, which is often the place where the intolerance starts; the waiting time is perceived as long and wasted. The lack of adequate space and interesting activities offered to their age group amplifies this impatience. To make more pleasant this time, the waiting rooms could be equipped with books, electronic devices and other tools that can offer adolescents fruitful activities. Another aspect of the setting is the possibility to organize moments completely dedicated to teenagers, whose visits may be concentrated in a single day or in a specific time. In this way, guys would feel in a more fit to them environment; furthermore, the visits placed in the afternoon, which is generally more "emptied" of medical figures, could contribute to their responsibility toward the care. Similar initiatives have already been carried out in some experienced centres, leading to good results. The **different timing of the visits** may be gradually proposed to each adolescent, to avoid the possibility of a trauma derived from the detachment from the paediatric phase.

Regarding the experience of therapy, which is also perceived as more and more cumbersome, it may be useful to propose the solution of the time flexibility, which it means the **possibility to choose the more comfortable time in which to do therapy**, according to their point of view. Sometimes, doing therapy in the evening is particularly annoying for kids, because they would like be together with friends and not have this thought, and they would appreciate to feel free from the task in the evening.

Even with teenagers, the appropriate **language** is important, to convey a concept of global growth and not only related to physical stature. In the case of communication of the diagnosis addressed to an adolescent, the real situation should be explained to her/him as soon as possible, but after a first communication with their parents, to make them aware and emotionally competent to support the daughter/son’s reaction. In this process, the physician should maintain the central position in the dialogue between the guy and the parents, avoiding the risk that parents put themselves at the centre of the relationship of care.

A very important other issue related to adolescents with GHD is their **autonomy and responsibility towards the cure**. Sometimes this result is difficult to achieve because of the excessive parents’ control, who continue to maintain the management of the therapy and the pathway. This phase could be further supported by specialized professionals such as psychologists, or through a peer counselling service. The **opportunities for sharing** among families who live the care for GHD could be expanded; this condition is mostly lived, in fact, at the individual and single-family unit level, while sharing with other families who have been through the same experience could have an important role in facilitating the empowerment of the care process. The occasions of sharing should be designed not only among parents but also among adolescents, who might be involved in creative activities to realize tools of information (brochures, short videos and others) addressed to other teenagers who live the same care for GHD. For example, some guys with GHD could be involved in the creation of a television spot to raise awareness on this condition.

As already emerged from the working group dedicated to children with GHD, if the empowerment and responsibility process starts from 7-8 children's years, in the following time the health care professionals can concentrate on the regular monitoring of the process, useful to understand how the adolescent is progressing in the management of therapy. To obtain this feedback, also a specific app set to periodically gather their impressions could be considered.

To consolidate adolescents' trust in the health care professional, it is useful to identify a **tutor of reference** who will follow them for the whole pathway.

Finally, to be able to communicate in the appropriate way with adolescents, **the health care professionals should be specifically trained and prepared to the correct approach to this complex world**.

The table below contains the identified actions to improve the communication between health care professionals and adolescents with GHD – *Table 2*

Theme	Action	How	Who
INTOLERANCE during medical visits	Working on SETTING OF CARE, to make the environment more fit to adolescents.	Waiting rooms equipped with books, electronic devices and other tools, to let adolescents to carry out pleasant and fruitful activities during the waiting for visits.	Health care management. Association like AFaDOC. Adolescents.
	Different timing of visits for adolescents.	Visits for adolescents with GHD concentrated in specific days and time, so thus to create a space completely dedicated to them. In this way, they could be more comfortable and responsible for their care.	Care team
INTOLERANCE toward therapy	Flexibility of treatment administration time.	Allow kids to choose the most comfortable time for them for the delivery of therapy, avoiding the obligation of the evening injection.	Care team. Parents.
	Appropriate LANGUAGE	Avoid an excessive focus on physical stature but convey a concept of global growth, not only physical.	Care team
AUTONOMY and RESPONSABILITY toward therapy	Communication among three subjects: physician, teenager with GHD, parents.	Since diagnosis, the referring physician can set up a direct communication with the teenager in care, as well as his/her parents, avoiding that the same parents place themselves at the centre of the caring relationship.	Paediatric Endocrinologist
	Specific support in cases of excessive	Support from psychologists, associations and peer	Psychologists. Associations like

	adolescent's dependence from parents.	consulting addressed to excessively present parents in managing therapy, who have problems in reducing their control and give their daughter/son autonomy, even with their growing age.	AFaDOC. Groups of parents who have already experienced the care for GHD.
	Sharing experiences addressed to adolescents with GHD's parents	Organization of moments of sharing among families who live the same course of treatment, to facilitate the empowerment process.	Associations like AFaDOC. Parents.
	Sharing experiences addressed to adolescents with GHD	Organization of moments of sharing among kids who live the same pathway and their engagement in activities aimed to increase the communication, knowledge and awareness on GHD condition. Eg. Realization of videos, commercials, brochures and other information material designed directly by teenagers for teenagers.	Associations like AFaDOC. Adolescents with GHD.
	Monitoring of adolescents' autonomy in managing therapy.	Once the autonomy process has been carried out, plan periodic meetings to follow up the progress of treatment and get feedback from the kids. Also digital tools can be useful in this phase, like a specific app designed to periodically gather their impressions.	Health care management. Care team. Associations like AFaDOC. Adolescents with GHD.
Improving services of care	Tutor of reference	Maintain the same physician of reference who follows adolescents all over the pathway.	Paediatric Endocrinologist. Health care management.
Communication of diagnosis	Gradual process: parents' acceptance first	Communicate the diagnosis prior to parents, to let them to express themselves, feel reassured and emotionally competent to communicate the diagnosis to their daughter/son, as soon as possible.	Care team. Parents.
TRAINING	Preparation of health care professionals to the knowledge and approach to the adolescents' world.	Training opportunities addressed to health care professionals who care for adolescents, for their knowledge and adequate preparation to communication	Health care management. Care team.

with them.

Group on communication toward children and adolescents with GHD’ parents

Participants:

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- *Giulia Anzilotti,* psychologist at Meyer Children’s Hospital, Department of Endocrinology, Florence;
- *Tommaso Aversa*, paediatrician endocrinologist at Gaetano Martino Polyclinic, Department of Endocrinology, Messina;
- *Isabella Catapano*, reference member of AFaDOC, Milan;

Facilitator: *Maria Giulia Marini*, director at Health Care and Wellbeing Area of ISTUD Foundation.

One of the most important element regarding children and adolescents with GHD’ parents is their strong affiliation to the centre of care, towards which they are very grateful. However, as shown by their narratives, their everyday life seems to be closed and made of much loneliness; the condition of GHD, in fact, is a few shared among parents, both within the family, because often a single parent takes care of the child’s care management and therapy alone - in most cases represented by mother– both toward the outside world. This context of loneliness must be taken into account by the care team, to support the parent/parents also in their daily difficulties. A form of support for these families is the **creation of a network**, a community of families and parents that would stimulate the sharing of experiences of care, doubts, fears, satisfactions, practical suggestions. To avoid an excessive burden on a single parent, the care team could, from the beginning of the pathway, invite the couple to the visits, or possibly involve other family member, setting a **communication addressed not only to a single subject but both parents**, to allow a real sharing of responsibility and commitment of the care.

Diagnosis is the first difficult moment in the care pathway for GHD for parents, who need to find a good support from the care team. This support can be done by following a biopsychosocial diagnostic model, going beyond the merely concept of clinical analysis and including, in addition to the communication of the physical parameters, the element of **listening to** and viewing by the physician of the other points of view - the emotional, social and family-based elements - in order to consider the overall context of the family in the planning of the care project. To avoid that diagnosis represents a "thunder out of the blue" and becomes a traumatic moment, it is preferred to **gradually prepare families** to the possibility of their child’s GHD condition, taking advantage of the occasions of meeting during the diagnostic tests and avoiding a too raw communication. Even the **setting of communication** is important, because it is necessary that parents are informed about the diagnosis without their child’s presence and in a safe place, allowing them to be free to express their instinctive reactions and doubts. Finally, the **language** is important to communicate in the right way the meaning of the GHD condition and the possible treatment, to avoid to focus too much on physical stature; as well as for children and adolescents, even parents should be conveyed a concept of global growth, which means not only to grow in stature but is linked to a general wellbeing. Physicians should constantly convey this concept of global growth all over the course of treatment, valuing other parameters in addition to the height.

The **choice to follow or not the GHD therapy** is delegated to parents, who could need a support for this decision. The physician can give from the beginning suggestions on how to obtain correct information from the internet channel, addressing them to appropriate websites and to local associations of reference. The associations, in fact, can have an important and strategic role in providing parents **neutral and scientific information about therapy** – using the appropriate language on the basis of their cultural level - and create opportunities for the exchange of experiences. Also **peer counseling** and the presence of **testimonials**, represented by adults who followed the GHD therapy and maybe become parents, can be useful. A further possibility for the exchange of experience is represented by the diffusion of the CRESCERE project and the collected narratives, which can be made available, through associations, to all families. It is finally important **not to impose timelines** in this phase of decision, parents need to follow their reaction time to assimilate information and take a decision, it is not helpful for them to hurry and feel pressure.

Another important issue in the parents' care management is their **children's autonomy in the administration of therapy**. The first element to consider is that, to start a process of child's empowerment, first of all parents must be reassured; therefore, they need **time** to feel calm and sure, without imposing physician's timelines. The achieved autonomy should represents a result and not a reason for sense of guilt. To reassure those who are in difficulties in leaving part of their management control, a communication that allows to **understand the practical benefits** of the child's autonomy could be useful, underlining the freedom derived from the elimination of the constant physical presence for the injection (for example, the possibility to be free to go on holiday by themselves). In particularly difficult cases, a more specific **support** can be offered to parents, presenting various possibilities: speaking only about psychological support may scare some of them, while they could appreciate to know about different and various forms of support, including psychological. In addition, parents may need to be supported also in fostering their children to autonomy; the care team can give them practical tips to value the possible achievements obtained from the autonomy, such as freedom (eg. "When you will be able to get therapy alone you will be able to do ...").

Even after the start of therapy, the **concern of side effects** remains an important issue for parents, sometimes scared by deviant information available on internet; the **constant dialogue** between families and providers of care is necessary, even at each visit, because allows to readjust such information and provide **constant reassurance**. The only opportunity for discussion in the occasion of the communication of diagnosis cannot be considered sufficient in a course of treatment so long and changeable over time. It is finally remarkable the value of the national health care system, which allows Italian families to benefit for free from this kind of therapy, very expensive and in some countries completely paid by families.

The following table shows the agreed actions to potentiate the communication between health care professionals and children with GHD's parents. – *Table 3*

Theme	Action	How	Who
SHARING THE CARE	Communication addressed to MORE THAN ONE FAMILY MEMBER.	To avoid that the load of the pathway management is on a single parent, invite to medical visits both parents or possibly another family member of reference, and direct communication to both.	Care team. Parents.
	Creation of a NETWORK	To diminish the families' sense of loneliness, stimulate the creation of a network among families who live the same course of treatment, helpful in reassuring them, answering to questions and supporting the difficult moments.	Care team. Associations, like AFADOC
COMMUNICATION OF DIAGNOSIS	GRADUAL preparation	To avoid that diagnosis is perceived as a unexpected and traumatic moment, take advantage of the opportunities of meeting during the examination and diagnostic tests to gradually prepare families to the possibility of a GHD diagnosis.	Care team
	LISTENING TO	Following a biopsychosocial model of diagnosis, together with the communication of clinical parameters, leave space for listening to the families and the observation of their context of reference - family, social, working, economic and emotional life. The context of reference can be integrated in the planning of care.	Care team
	Attention to the SETTING OF CARE	A protective environment can facilitate the moment of the communication of diagnosis. Prefer secluded places where parents can feel free to express their instinctive reactions, without their children.	Health care management. Care team.
	Adequate LANGUAGE	Avoid an excessive focus on physical stature, but convey a concept of "global growth", not only physical, which diminish the	Care team

		importance of the result.	
THE CHOISE OF THERAPY	Responsible use of information channels.	The health care professionals can support parents in their choice to follow the GH therapy or not, guiding them in finding reliable, clear and neutral information. Specifically, they can address to scientific websites and those of local associations, to avoid they encounter confounding information.	Care team. Associations, like AFADOC
	Support from ASSOCIATIONS	The associations can play an important role in providing neutral and "evidence-based" information, declined on the cultural level of each family.	Associations, like AFADOC.
	Outreach groups	Supporting groups among families can be established, so that those who have already faced the choice of therapy can talk to those who pass through the same doubts. In these groups it can also be foreseen the presence of adult testimonials who followed the GH therapy in the past.	Associations, like AFADOC. Families who are living or already lived the pathway for GHD. Testimonials.
	Sharing of stories	The stories collected within the CRESCERE project can be further disseminated through the local associations' channels.	Associations, like AFADOC. Centres of care.
	Do not impose deadlines	Let each family metabolize the diagnosis and the choice of therapy, according to their reaction time, avoiding to hurry and put pressure.	Care team.
CHILDREN'S AUTONOMY AND RESPONSABILIZATION toward their care	REASSURING parents	The first element necessary to start a process of children's empowerment is the parents' reassurance and determination to reduce their control in the management of therapy. Leaving time to assimilate this process, the autonomy will represent for families a result and not a reason for sense of guilt.	Care team
	VALUING ADVANTAGES FROM CHILDREN'S AUTONOMY	The health care professionals may foster the gradual patients' transition to autonomy through a communication addressed to the parents that values the advantages represented by the achieved independence, in terms	Care team

		of greater freedom and easier daily therapy management. This argument can also be suggest to the parents themselves to help their children in cases of difficulties to administer the self-therapy, stimulating them through the idea of the conquer of greater freedom.	
	Specific supports	In cases of particular parents' difficulties to leave the autonomy to their daughter/son, a variety of supports can be offered, not limited to the psychological service - which sometimes scares - but including counseling and peer counseling .	Care team. Psychologist. Associations like AFADOC. Parents who already faced the GH therapy.
SIDE EFFECTS of therapy	Continuing REASSURING	In addition to the explanations provided at the beginning of therapy, health care professionals should constantly reassure families by providing further explanations, if necessary at each visit, to avoid giving for granted some concepts that have been transmitted once. Over the years and throughout the different phases of the development of therapy, in fact, parents can get lost and become insecure.	Care team.

Final remarks

What emerged from the Consensus and the three thematic groups' work reveals a uniformity in the main themes of interest and the identified actions to improve the communication in the pathway for GHD. Beyond the proper differentiation among children, adolescents and their families, the work carried out by the involved health care professionals and representatives of associations represents a shared "modus operandi" identifying the main actions which involve all the stakeholder.

The first common issue expresses by all the three working groups is the **setting of care**, represented not only by the place of visits but also by the waiting rooms, which are not considered as secondary but on the contrary are perceived as an integral part of the experience of care, both from patients and their family members. In these places, in fact, patients spend lot of time waiting for the medical visit, for this reason some interesting and pleasurable activities could be offered, so thus to let patients to relax, exchange experiences with others, enjoy the waiting and improve the living with the hospitalization. There are differences in the patients' points of view: children need to calm down and feel less "hospitalized"; adolescents could appreciate more attractive activities related to their age and a less infantilized context; finally, parents need a space for pair discussion and a safe environment in which to communicate with health care professionals and feel free to express their emotions derived from the communication of the diagnosis or specific moments of discouragement or doubts. The setting of care is therefore an important element of the process of communication between health care professionals and families. It can be considered as the first form of communication, a sort of card that transmits an immediate idea of the pathway.

The second issue is the importance of using an adequate **language**, a concept concretely described basing on the daily clinical practice. The language should be modulated on the basis of the patients, but what that can be extended to everyone is the concept of "**global growth**", to be conveyed to children, adolescents and their parents; growth, in fact, is not simply reduced to stature and physical parameters, but it is connected to the wellbeing and the general growth of all the individual's aspects. If this message is transmitted from the beginning of the care, it can make the difference in the living with therapy and medical visits, because the result of therapy is not overvalued and can be more appreciated as integrated to other elements. The GHD can be communicated as something that is lacking at the moment and can be recovered, illustrating the condition not as a matter of physical stature but a general wellbeing.

This issue is particularly important during the **communication of the diagnosis**, a phase of the pathway considered crucial by all the three consulted points of view. This moment can be carried out following a sequence that foresees a first communication addressed only to parents, to give them the space to freely express their instinctive reactions, doubts, fears and doubts. Later, parents should be ready to communicate, together with the physician of reference, the condition of growth hormone deficiency to their children.

Another common issue is the **children and adolescents with GHD's autonomy and responsibility toward the care**. This is important in all the phases of the pathway, since the process of fostering to autonomy can start from 7-8 years children. The support to autonomy must continue till the end of the care, since even when children become teenagers, they need to be constantly monitored in their management of therapy, throughout the collection of their feedback and keeping always open the channel of communication with them. Nevertheless, this process starts from their parents, because without their reassurance and conviction about that, it is very difficult to set a positive transition of care. For this reason, the issue of autonomy is closely linked to that of **gradualness,** which is necessary to foster children through the first steps of acquisition of awareness on the pathway. The decision-making freedom should be given over the time, trying to avoid that adolescents could feel a sense of "abandonment" but rather valuing this passage as a conquer of freedom. Graduation is also to be maintained with parents, because each of them needs a specific time to metabolize and accept the situation, to make a choice on the treatment, to give part of their control to their children. Not respecting the graduation and imposing timelines could lead to sense of guilt and tension. The healthcare professionals' task, not always easy to carry on, is to foster this process through a constant communication to reassure, support, value the positive aspects of the children and adolescents’ autonomy. The active involvement of patients in this process allows them to be aware of the value of the care and better face the daily commitment.

Finally, the theme of the **sharing** of the experience of care regards children, adolescents and their parents. The emerged scenario indicates a general families’ loneliness in facing the care for GHD. The experience of care tends to be lived within the household and there are a few opportunities for sharing. Specifically, children may be stimulated by comparison with their peers both in training to therapy and in the whole pathway, which could be more enjoyable. Adolescents could be involved in interesting activities, useful to reduce their growing sense of impatience and to create opportunities for discussion among them. Loneliness is frequently found especially among parents, which could be addressed to a network of reference that can accommodate their concerns, need for reassurance and comparison. These opportunities for sharing can be considered an element of the communication of care, since sometimes the times of the medical visits not allow families to fully express themselves; health care professionals can find in this network the opportunity to inform families in a more neutral and in the same time close to them way.

The **experience of the Consensus** has been based not on abstract concepts but from a concrete research represented by the CRESCERE project, which gave more awareness to the Consensus. Through an intensive work, participants reached the agreement and shared practical indications to strengthen the communication in the course of treatment for GHD. This document is therefore the result of a work that actively involved all the participants, which at the end of the experience declared to be satisfied and willing to widespread the work to other stakeholders involved in the pathway for GHD. The document will be diffused among the expert centres of care and will be accessible to all the health care professionals who wish to improve their relationships of care in the daily practice. Finally, part of the outcomes of the Consensus are exportable to other Paediatric areas.