

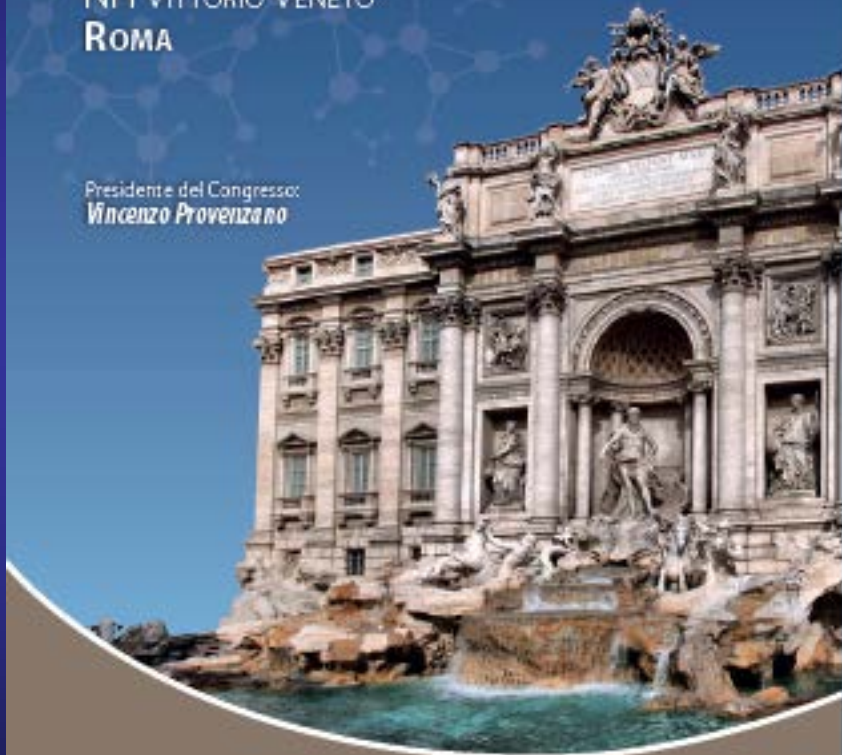
XVI CONGRESSO NAZIONALE

29-31 marzo 2017

NH VITTORIO VENETO

ROMA

Presidente del Congresso:
Vincenzo Provezano



Piernicola Garofalo

*“La tecnologia nel bambino
e nell’adolescente
diabetico”*

Il sottoscritto *Piernicola Garofalo*

in qualità di Docente del presente corso,
consapevole che chiunque rilascia dichiarazioni mendaci è punito
ai sensi del codice penale e delle leggi speciali in materia, ai
sensi e per gli effetti dell'art. 3.3 sul Conflitto di Interessi, pag.
17 del Reg. Applicativo dell'Accordo Stato-Regione del 5
novembre 2009

DICHIARA

che negli ultimi due anni ha avuto rapporti diretti e indiretti di
consulenza con finanziamenti con le seguenti ditte, portatrici di
interessi commerciali in campo sanitario:

**Merck-Serono, Lilly, Ferring, Italfarmaco,
Novo Nordisk, Pfizer, IBSA,
Novartis-Sandoz, Menarini**

WHO Terminology

- **Adolescents**: People aged 10-19 years
- **Young people**: People aged 10-24 years

Adolescence subgroups

- **Early**: 8-11 years
- **Middle**: 12-16 years
- **Late**: 17-20/24 years

TRANSIZIONE: definizione

Society for Adolescent Medicine “ Position Paper” (1993) : :

“Un passaggio, programmato e finalizzato, di adolescenti e giovani adulti affetti da problemi fisici e medici di natura cronica, da un sistema centrato sul bambino ad uno orientato sull’adulto

La transizione è importante per tutti i teenagers, anche per i soggetti sani ”

P.S. La Società di Medicina dell’Adolescenza (SAHM) amplia i limiti cronologici dell’adolescenza ponendoli fra 10 e 24 anni!



Quando è la transizione ?

PEDIATRA 10-14

PEDIATRA/ADULTO 16-18

ADULTO 20-24

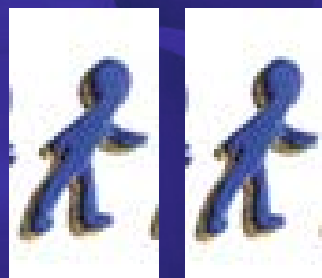


Stato dell'arte

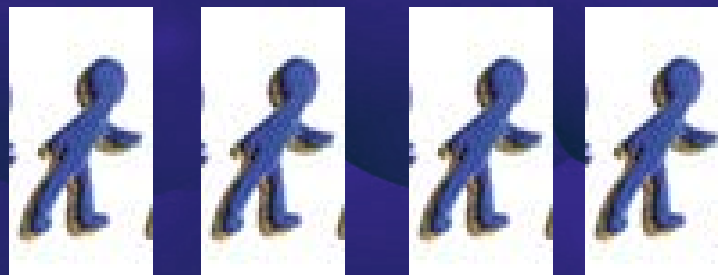
- 4/10 PEDIATRA LONG-TERM



- 2/10 TRANSITION TO ADULT



- 4/10 DROP-OUT



Drop-out after the Transition Phase

Table 2
Drop-out rate in different endocrine disorders after transition to adult health care service.

Disease	Reference	Number of patients	Age at transition (years)	Drop outs	Issue of the study	Method
Congenital adrenal hyperplasia	Gleeson et al, 2013 [4]	61	Male 18 [17–19] Female 19 [18–21]	Total 21 (34%) 50% of patients referred to tertiary specialist care	Young persons clinic (transition) had no positive impact on follow up rate	Clinic records and appointment systems
Turner Syndrome	Freriks et al, 2011 [5]	150	Unknown	30% All were not treated in the paediatric centre that transfers to the adult clinic.	Evaluation for previously undiagnosed morbidity	Clinical records of adult clinic mean age of analysed patients was 31 years
Turner Syndrome	Pedreira CC et al, 2005 [6]	39	Unknown	36.8% without regular follow up	Surveillance of treatment and comorbidities	Cross sectional evaluation with advertisement, mean age 30 years
Turner Syndrome	Verlinde F et al, 2004 [7]	102	18.2 years	12.7% not under regular follow up	Treatment and psychological evaluation	Questionnaire sent out by the Belgian Study Group for Paediatric Endocrinology
Congenital adrenal hyperplasia, Hypogonadotropic hypogonadism, Growth hormone deficiency	Godbout et al, 2012 [2]	153	19,4 Jahre	19.6%	Evaluation of patients opinion on transfer in a single centre	Questionnaires sent out
Diabetes	Busse et al, 2006 [3]	101	17.8 ± 0.9 years (median 18 years)	3% no medical treatment 28.7% without diabetologist	Patients opinion on transfer in a single centre	Structured telephone interview by one observer

Developmental tasks of adolescence

Biological

Psychological

Social

Early adolescence

Early puberty. Girls: breast bud and pubic hair development, start of growth spurt. Boys: testicular enlargement, start of genital growth

Concrete thinking but early moral concepts; progression of sexual identity development; possible homosexual peer interest; reassessment of body image

Emotional separations from parents; start of strong peer identification, early exploratory behaviours (smoking, violence)

Mid-adolescence

Girls: mid-late puberty and end of growth spurt; menarche; development of female body shape with fat deposition.

Boys: mid-puberty, spermatogenesis and nocturnal emissions; voice breaks; start of growth spurt.

Abstract thinking, but self still seen as “bullet proof” growing verbal abilities; identification of law with morality; start of fervent ideology (religious, political)

Emotional separation from parents; strong peer identification; increased health risk (smoking, alcohol); heterosexual peer interest.

Late adolescence

Boys: end of puberty; continued increase in muscle bulk and body hair

Complex abstract thinking; identification of difference between law and morality; further development of personal identity; further development of or rejection of religious and political ideology

Development of social autonomy; intimate relationships; development of vocational capability and financial independence



- **Delusione traumatica** (corpo = complessi e paure)
- **Regressione** (difesa dall'angoscia)
- **Rottura dell'appartenenza** (corpo = oggetto estraneo)
- **Sospensione e incertezza** (corpo = oggetto da curare e non mezzo per relazionarsi)

***Coscienza del corpo malato
in adolescenza***

- 1. *controlli clinici e monitoraggi*** (interruzione continuità esistenziale);
- 2. *riacutizzazioni e complicanze*** (senso di fallimento, precarietà, interruzione esistenziale);
- 3. *immagine corporea deturpata*** (effetti collaterali farmaci, cicatrici, cateteri, debolezza, astenia, effetti patologici sui ritmi di crescita, etc rendono più faticoso il confronto con il sé e con i coetanei)

L'Adolescente con malattia cronica

Adolescents and Chronic Conditions – Can they peacefully co-exist?

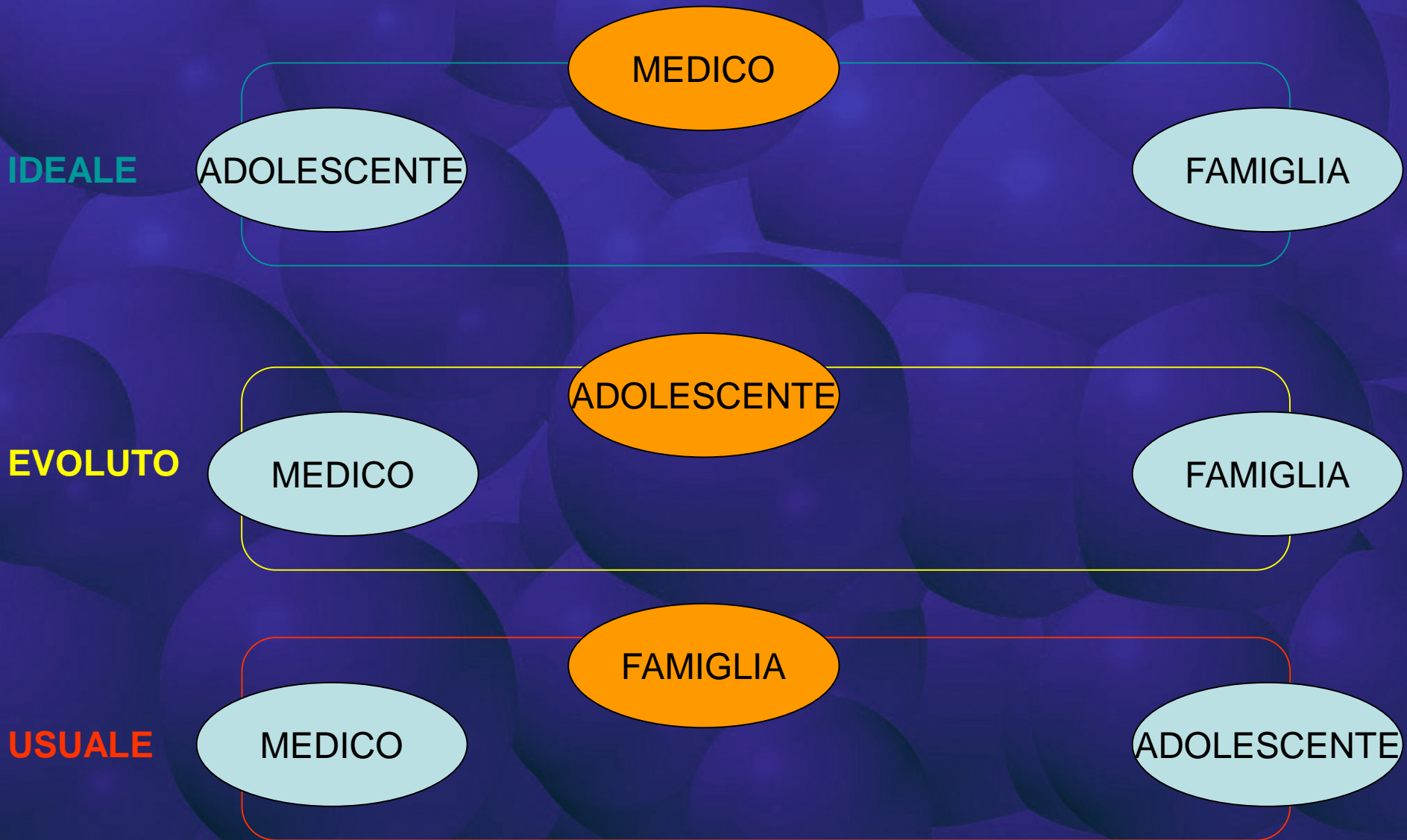




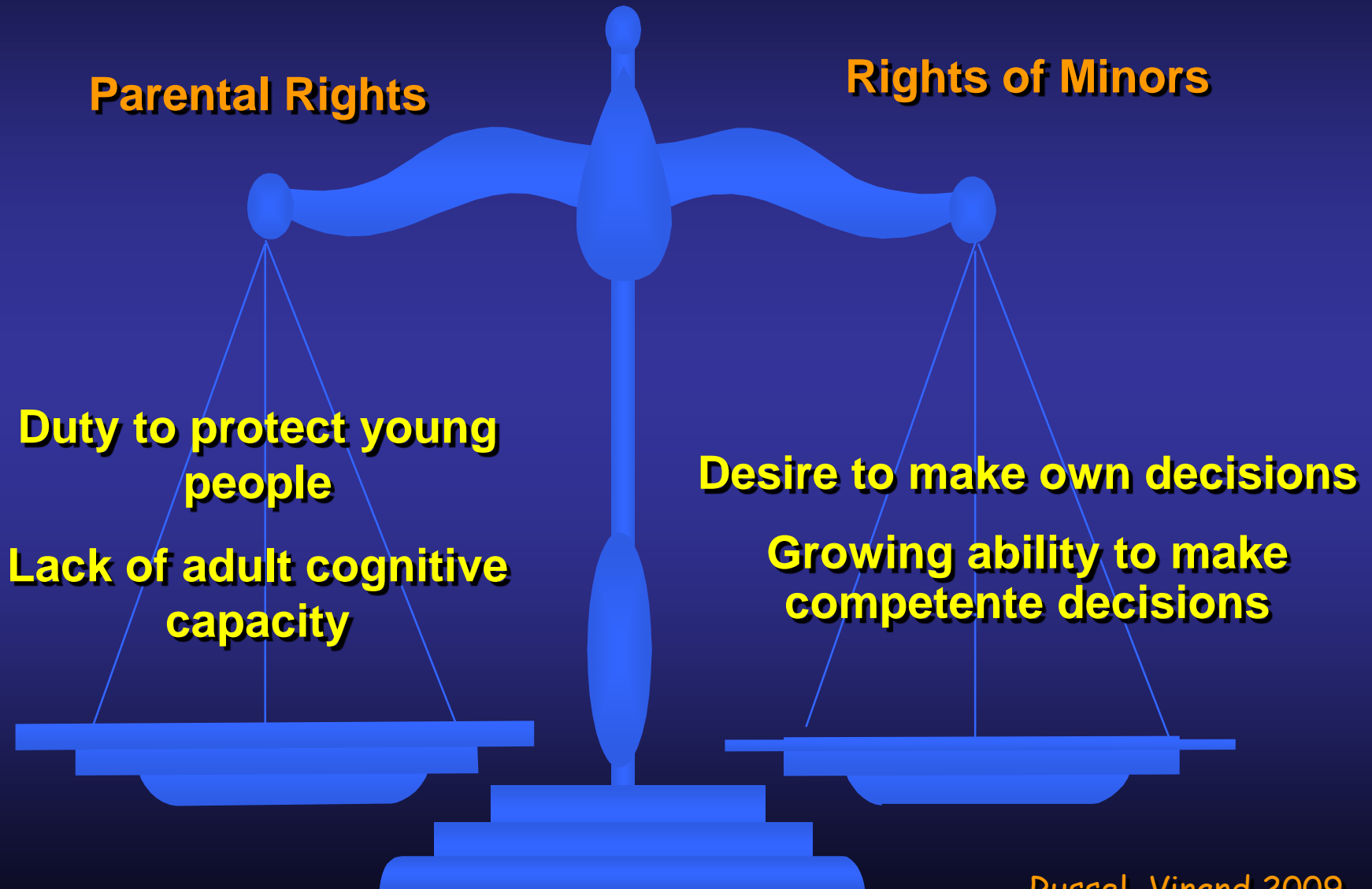
***“La crescita umana
inizia nella biologia e
termina nella cultura”***

(Palmonari, 2001)

La specificità del rapporto



Balancing rights and responsibilities in adolescent care





(Ginott,1971)

***“I genitori hanno bisogno
di essere indispensabili ai figli.
I figli hanno bisogno
di non aver bisogno dei genitori”***

IL MINORE ADOLESCENTE NEL DIRITTO CIVILE

AL 18^{mo} ANNO = ACQUISIZIONE DELLA "CAPACITA' DI AGIRE" (CON LA MAGGIORE ETA');

AL 16^{mo} ANNO = POSSIBILITA' DI CONTRARRE MATRIMONIO, DI RICONOSCERE FIGLI NATURALI, DI CHIEDERE IL DISCONOSCIMENTO DI PATERNITA', DI IMPUGNARE IL PROPRIO RICONOSCIMENTO;

AL 14^{mo} ANNO = POSSIBILITA' DI INTERVENIRE NEL PROPRIO INTERESSE ED IN QUELLO DEL MANTENIMENTO DELL'UNITA' FAMILIARE;

AL 12^{mo} ANNO = POSSIBILITA' DI INTERVENIRE IN TEMA DI ADOZIONE;

AL 10^{mo} ANNO = RILEVANZA IN TEMA DI TUTELA.

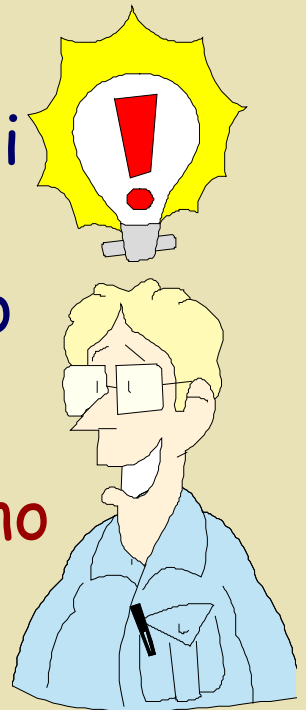
Il minore adolescente nel Diritto Penale

Nell'ambito del **Diritto Penale** italiano l'adolescente e, comunque, il minore sono oggetto di particolare attenzione sotto il duplice profilo sia di un trattamento più benevolo quando essi sono autori di atti illeciti che di una maggiore severità nei riguardi di chi abusa di loro.

Il principio fondamentale è che sotto i 14 anni non si è mai imputabili (art. 97 CP) e che tra i 14 ed i 18 anni si è imputabili solo se si dimostra, caso per caso, il raggiungimento della capacità di intendere e di volere ma, comunque, la pena è diminuita fino ad un terzo (art. 98 CP).

MA QUANDO IL MINORE POTRA' ESPRIMERE UN CONSENSO VALIDO?

1. Solo dopo il conseguimento della maggiore età, in accordo con l'art. 2 del Codice Civile;
2. Dopo il superamento del 14° anno di vita e con l'acquisizione della capacità di intendere e di volere, rifacendosi alle norme del Codice Penale che disciplinano l'imputabilità;
3. Comunque anche tra il 14° e il 18° anno purché venga preliminarmente e con attenzione accertata la sua maturità critica e decisionale.



MINORI E CONSENSO INFORMATO

Appare scontato che l'adolescentologo quanto e, forse, più di ogni altro medico debba rispettare (se non altro nel proprio interesse) i diritti del malato. Il primo di tali diritti è stato sancito anche dall'art. 32 della Costituzione Italiana, laddove si stabilisce che “*..nessuno può essere obbligato ad un determinato trattamento sanitario se non per disposizione di legge...*”. Tale principio viene, per altro, confermato anche dall' art. 31 del Nuovo Codice di Deontologia Medica (CDM) dove si stabilisce che “*..il medico non deve intraprendere attività diagnostica e terapeutica senza il consenso del paziente validamente informato..*”.

Consenso informato o “permesso” informato?

Sta di fatto che il termine consenso si riferisce ad un'autorizzazione ad agire per conto e nell'interesse del consenziente ma solo su un proprio bene disponibile: pertanto, il consenso espresso da un genitore o da un tutore per conto di un minore andrebbe definito più esattamente permesso informato (*informed permission*, come suggerito dall'American Academy of Pediatrics e non più *informed consent*).



Morta dopo il rifiuto della chemio: legali, era la volontà di Eleonora



Il caso della 18enne riapre il tema della libera scelta delle cure: parte un'inchiesta della Procura

Autonomia e competenza in età adolescenziale

Le zone grigie

- Accesso alle prestazioni di P.S.
- La contraccezione
- La diagnostica tossicologica e sierologica
- La diagnostica per immagini
- Gli interventi terapeutici in urgenza
- Quale parentalità (bigenitorialità vs monogenitorialità)



IL MEDICO DI FRONTE ALLA
RECENTE NORMATIVA SULLA
TUTELA DELLA PRIVACY



The Need for a Privacy Standard for Medical Devices That Transmit Protected Health Information Used in the Precision Medicine Initiative for Diabetes and Other Diseases

Abstract

Privacy is an important concern for the Precision Medicine Initiative (PMI) because success of this initiative will require the public to be willing to participate by contributing large amounts of genetic/genomic information and sensor data. This sensitive personal information is intended to be used only for specified research purposes. Public willingness to participate will depend on the public's level of trust that their information will be protected and kept private. Medical devices may constantly provide information. Therefore, assuring privacy for device-generated information may be essential for broad participation in the PMI. **Privacy standards for devices should be an important early step in the development of the PMI.**

**K.Britton -J.Britton Colonnese: J.of Diab. Science and
Technology -March 2017**

DIABETES TECHNOLOGY & THERAPEUTICS
Volume 16, Supplement 1, 2014
© Mary Ann Liebert, Inc.
DOI: 10.1089/dia.2014.1513



ORIGINAL ARTICLE

Diabetes Technology and the Human Factor

Alon Liberman¹, Bruce Buckingham², and Moshe Phillip¹

Comment

This study emphasizes that changing to more intense insulin regimens, including diabetes technologies (i.e., CSII and CGM), is correlated with certain socioeconomic and sociodemographic characters such as ethnicity, families with higher income, higher parental education, and private health insurance. It is also associated with better glycemic control and lower HbA1c levels. These findings are consistent with several studies indicating that social support and socioeconomic status (3) (and not only the patient's personal or subjective experience) have a major influence on the adherence potential both in diabetes in general and in diabetes technology regimens.

Comment

The subjective experience of patients concerning the use of diabetes technology has a significant effect on both patients' quality of life and adherence to diabetes regimen. The studies cited above provide complementary aspects of this important issue. As one can see, the question of what makes a device satisfactory relies heavily on the patient's expectations, values, and developmental stage.

Children preferred significantly the convenience in wearing the device and were not concerned with effectiveness as compared to adults. This finding is understandable based on our knowledge of how adolescents have a problem in appreciating the significance of future diabetes complications. It also reflects the difficulty of children and youth to tolerate inconveniences and to have deferred gratification (1,2).

Patients may also have different views about using the same device. While some patients feel that a certain technology improves their quality of life significantly, others may feel that the same technology is causing a burden. Good or bad experiences can influence the patients' motivation and emotional well-being. The knowledge obtained from patients' subjective experience can help the diabetes team to develop a psychoeducational protocol that answers issues that are relevant to the patient and help to prevent diabetes technology drop-outs. As we move to in-home, in-school, and in-work closed-loop systems, it will be critical to do user evaluation studies to assess the perceived hassles of using the device as compared to the perceived benefits. What a team of engineers considers easy to use and successful may not be perceived by children, adolescents, and adults as user friendly and beneficial. Perceived benefits are best accepted if they are immediate, not delayed.

ceived by a CGM user as beneficial. A 0.3% decrease in A1C levels or a 5% improvement in the percent of readings in range may be statistically valid, but will not have an immediate perceived benefit to the adolescent. It will be critical that any burden of using and wearing more devices with communications issues between devices is offset by immediate benefits to the user in observed CGM readings.

Recruitment Into a Pediatric Continuous Glucose Monitoring RCT

Patient and Recruitment Process Characteristics Associated With Decision to Participate

Conclusions:

Recruitment is a critical and often challenging phase of clinical trials.

Recruitment to pediatric CGM

studies may be especially challenging due to youths' reluctance to use CGM.

These data provide an opportunity to better understand and possibly optimize recruitment into future pediatric CGM studies and other studies of advanced diabetes technologies.

L.K. Volkening, K.C. Gaffney, M.L. Katz, L.M.Laffei;

J.of Diab. Science and Technology - January 2017

...per saperne di piu'...

- Diabetes Technology Society
www.diabetestechology.org
- Journal of Diabetes Science and Technology
- www.journals.sagepub.com

- *Clinical Diabetes Technology Meeting*
- *Houston Texas- April 21-22, 2017*

- *Diabetes Technology Meeting*
- *Bethesda, Maryland -November 2-4, 2017*



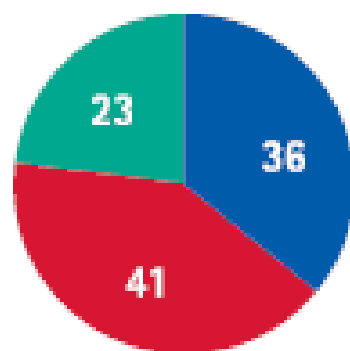
*Aderenza alla terapia:
la via dopo l'appropriatezza*

La definizione di **aderenza** è stata stabilita da World Health Organization nel 2003.

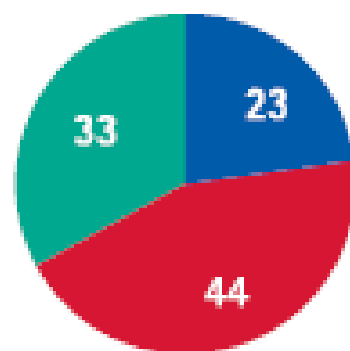
“...il livello di comportamento dell’individuo che prende un farmaco, segue una dieta e/o cambia stile di vita in seguito alla raccomandazione di un sanitario”

(“...the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a healthcare provider”).

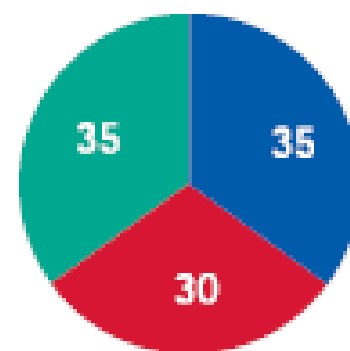
Genitori di bambini
(età 4-12)



Adolescenti
(età 13-17)



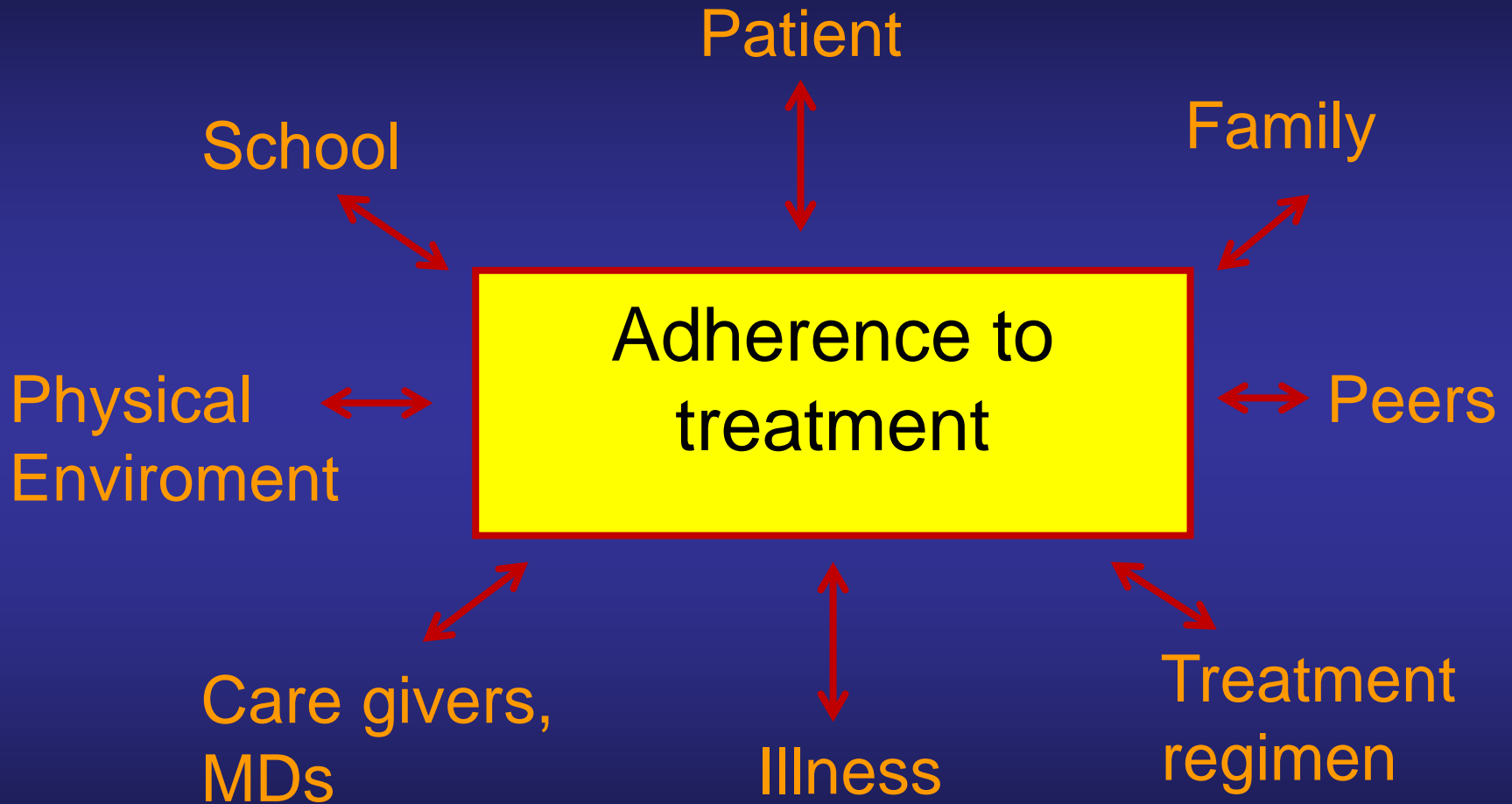
Adulti
(età 18+)



■ Strettamente aderenti

■ Occasionalmente non aderenti

■ Non aderenti o scettici



1369-6998

doi:10.3111/13696998.2011.597808

Article 0034.R1/597808

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Review

Pharmacoeconomic aspects of poor adherence: can better adherence reduce healthcare costs?

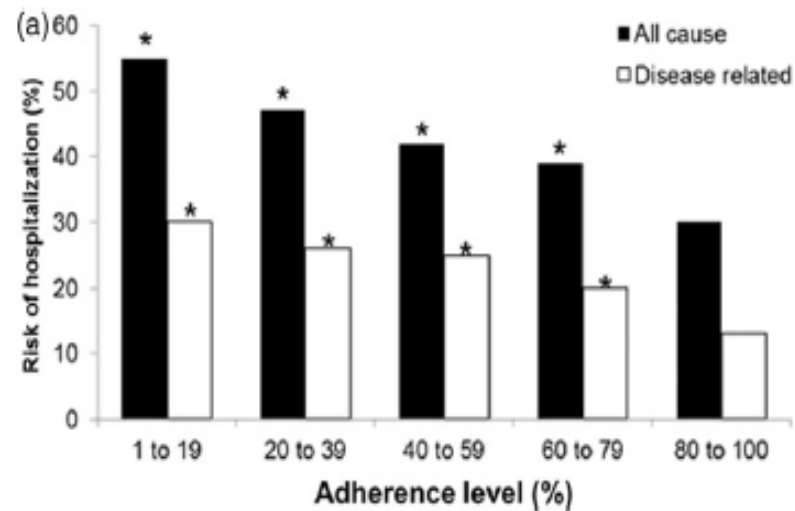
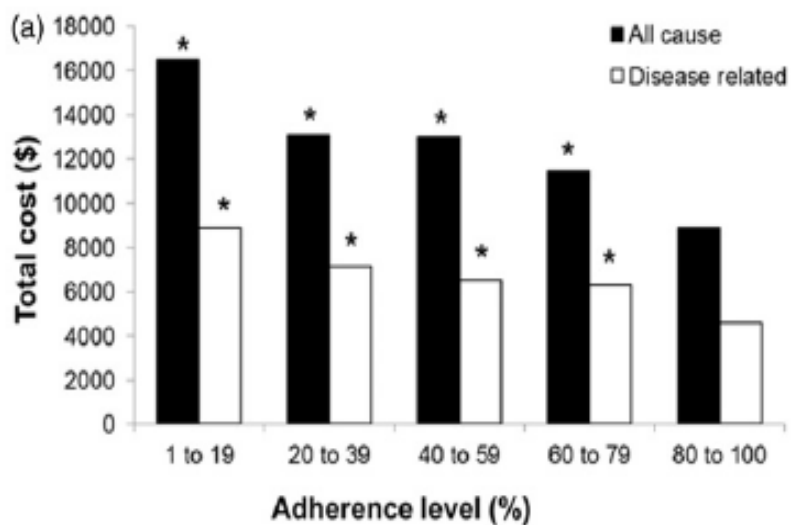
Alain Golay

Division of Therapeutic Education for Chronic
Diseases, University Hospital Geneva, Switzerland

Abstract

Background:

Poor adherence to medical treatment is one of the main reasons why patients do not achieve the full benefits



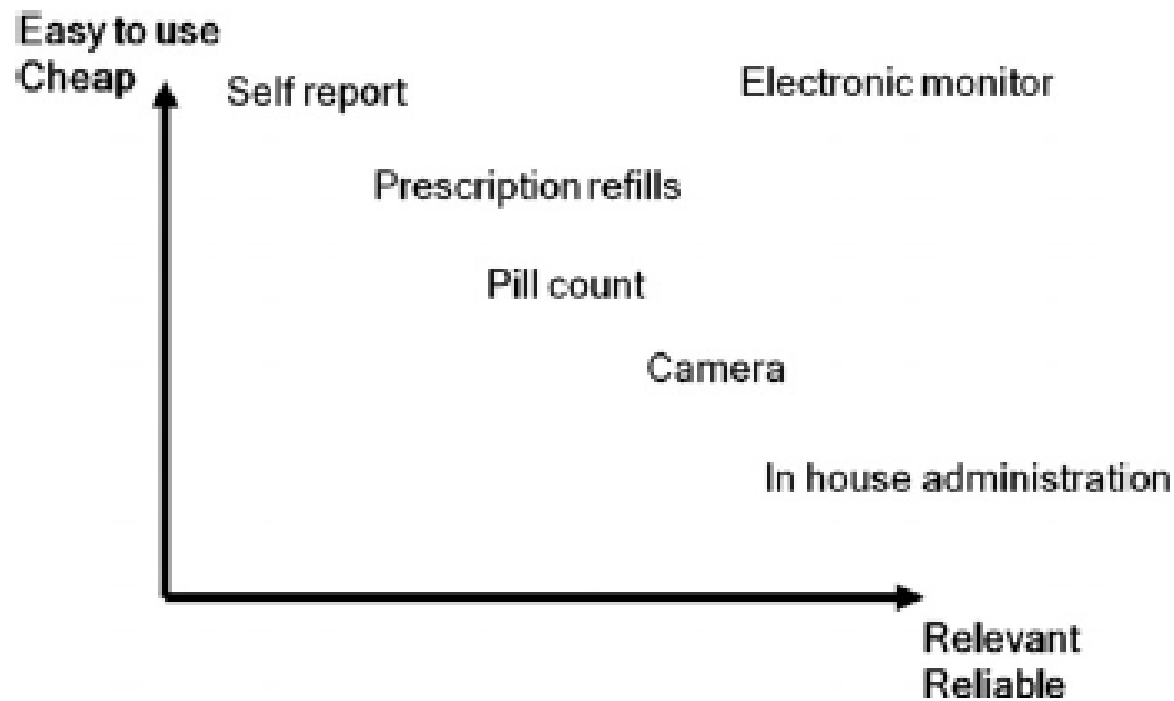


Figure 3. Trade-off between costs and benefits of various types of adherence monitoring systems (from Norgren S. *Pediatr Endocrinol Rev* 2009;6(Suppl 4):545–8. Used with permission)²⁰.

Adherence to Insulin Pump Behaviors in Young Children With Type 1 Diabetes Mellitus Opportunities for Intervention

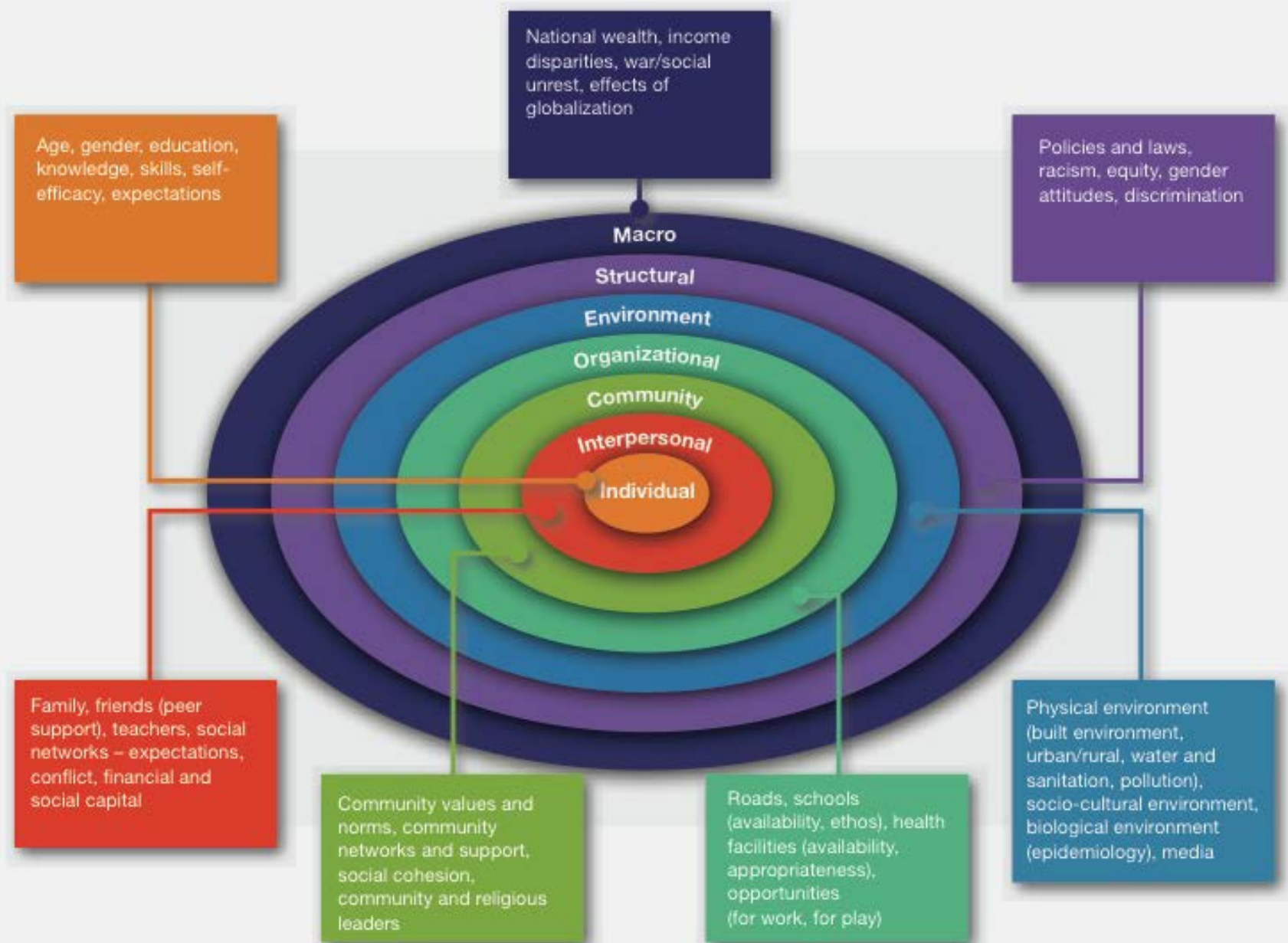
Conclusions:

Parents of young children adhered to individual pump behaviors, but showed some variability in their adherence to *Wizard*/Bolus Advisor steps. Parents showed low adherence to recommendations to correct for hyperglycemia. **Like adolescents, targeting pump behaviors in young children may have the potential to optimize glycemic control.**

S.R. Patton, K.A. Driscoll, M.A. Clements;

J..of Diab. Science and Technology - January 2017

The determinants of adolescent health and development: an ecological model





Corso Fad con tutoraggio

GESTIONE DEL DIABETE E DELL'OBESITA' NELL'ETA' DI TRANSIZIONE

1 marzo 2017 – 31 dicembre 2017
Ore formative: 10- Crediti formativi 15

Segreteria Organizzativa e provider ID n. 1463
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Via Farini 28, 40124 Bologna

RESPONSABILE SCIENTIFICO
Dott. Piernicola Garofalo
UOC Endocrinologia AOOR "Villa Sofia- Cervello"- Palermo



1. Strumenti e metodi

P. Garofalo

2. "La rivoluzione digitale" nella sanità e nelle malattie croniche

C. Cipolla

3. Hot Topics dell'età di transizione

P. Garofalo

4. La transizione nelle patologie croniche

R. Gaudino

5. L'educazione nutrizionale dell'adolescente con sovrappeso – obesità

A. Vania



6. Ruolo del pediatra di famiglia nella prevenzione e nel controllo dell' obesità in età evolutiva

S. Chiavetta

7. Il bambino obeso metabolicamente sano, metabolicamente malato

G. Farello

8. L' obesità: sport e prevenzione

G. C. Pozzobon

9. L' adolescente affetto dalla obesità e la compliance alle diete

R. Tanas

10. Il diabete in età evolutiva: la prevenzione della chetoacidosi diabetica

B. Predieri



11. Diabete mellito tipo 1 - transizione, continuità assistenziale dalla diabetologia pediatrica alla diabetologia in età adulta

B. Predieri

12. Disturbi del comportamento alimentare in età evolutiva, appropriatezza degli interventi, transizione e rischio di drop out

S. Marucci

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R.I.M.A.

SUPPLEMENTI R.I.M.A.

FOLIA



RICHIESTA PATROCINIO

Publicato il 30 gennaio 2014



MODULO PRIMA ISCRIZIONE O RINNOVO ANNUALE

Publicato il 20 gennaio 2014

Email: info@medicinadelladoloscenza.com

L'adolescentologo è un medico del tutto particolare,
esperto nelle cure, sensibile nell'ascolto, pronto
nell'intervento...

...un mix di competenze e vocazione, di abilità
professionali e umane, di idoneità alla comunicazione
nella sua duplice componente di ascolto e di efficace
interazione verbale.

Nicola Garofalo

"Impariamo a guardarli"

Sperling & Kupfer 2004

Igualdad no es siempre sinónimo de justicia



Esto es igualdad



Esto es justicia

Comment

Adherence is a significant issue in diabetes treatment, and there are several potential advantages of using this new questionnaire. First of all, it was simplified to allow the patients and their caregivers to answer the questions online without the need for a trained professional to be with them to administer the questionnaire. This allows for the possibility of doing large Internet-based surveys. In addition, it has different versions for patients using either conventional injections or insulin pump therapy, making it more sensitive to the unique aspects of adherence with these two modes of therapy. The authors sought to identify the specific components of adherence to different aspects of the diabetes regimen (insulin administration, blood glucose measurements, carbohydrate counting, physical activity, and CSII management). The questionnaire was built on both patients' interviews and diabetes experts' reviews. This method represents a very balanced approach that takes into consideration the patients' point of view about their diabetes in order to improve their functioning.

Comment

Parents and caregivers of children with diabetes experience a heavy burden as a result of the demands of the diabetes regimen requirements and the anxiety about their child's health and even life. The efforts are endless and deal with unexpected eating patterns, extreme glucose variability, and inconsistencies in insulin sensitivity. The anxiety caused by the possible consequences of severe hypoglycemic or hyperglycemic events to the young child can affect both the parents' quality of life and daily functioning. Another challenging situation is sending the child to school without the parents' direct supervision and often without a professional team or even a person who knows how to manage diabetes.

These two interesting studies suggest that increasing the use of diabetes technologies among children and even young children can help ease this burden. The studies indicate that using technological devices is both safe and feasible. These findings are concordant with previous studies that showed the potential of using diabetes technologies in children (4).



World Journal of
Diabetes

Submit a Manuscript: <http://www.wjgnet.com/esps/>

Help Desk: <http://www.wjgnet.com/esps/helpdesk.aspx>

DOI: 10.4239/wjcd.v6.i8.999

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EDITORIAL

Impact of new technologies on diabetes care

Elisa Giani, Andrea Enzo Scaramuzza, Gian Vincenzo Zuccotti

Abstract

Technologies for diabetes management, such as continuous subcutaneous insulin infusion (CSII) and continuous glucose monitoring (CGM) systems, have improved remarkably over the last decades. These developments are impacting the capacity to achieve recommended hemoglobin A1c levels and assisting in preventing the development and progression of micro- and macro vascular complications. While improvements in metabolic control and decreases in risk of severe and moderate hypoglycemia have been described with use of these technologies, large epidemiological international studies show that many patients are still unable to meet their glycemic goals, even when these technologies are used. This editorial will review the impact of technology on glycemic control, hypoglycemia and quality of life in children and youth with type 1 diabetes. Technologies reviewed include CSII, CGM systems and sensor-augmented insulin pumps. In addition, the usefulness of advanced functions such as bolus profiles, bolus calculators and threshold-suspend features will be also discussed. Moreover, the current editorial will explore the challenges of using these technologies. Indeed, despite the evidence currently available of the potential benefits of using advanced technologies in diabetes management, many patients still report barriers to using them. Finally this article will highlight the importance of future studies tailored toward overcome these barriers to optimizing glycemic control and avoiding severe hypoglycemia.

Electronic monitoring can also help identify opportunities to intervene to improve adherence and motivate patients to take their medicine. Prospective studies using electronic monitoring suggest that patients with diabetes took between 67% and 85% of doses of oral hypoglycemic agents as prescribed. Electronic monitoring identified poor compliers and the subsequent use of interventions improved adherence by between 61% and 79%. Monitoring suggested that elevated glucose or HbA_{1c} levels were related to missed doses and not under-prescribing³⁶.