

Developing Concordance in Work with Children and Adolescents



Image: Focus Forward Counselling

Justine Duranti



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Help Reduce our Student Nurses Confusion!

‘The patient is **non concordant** with his medicines.’

‘If the psychiatrist switches the patient to a depot injection his **concordance** will be increased.’



NICE (2018)

‘When prescribing stimulants for ADHD, think about modified-release once daily preparations for the following reasons: Convenience, **improving adherence and** reducing stigma ...’

‘**Tell people** that stimulant medication does not change personality.’

No mention of concordance and 26 references to adherence!

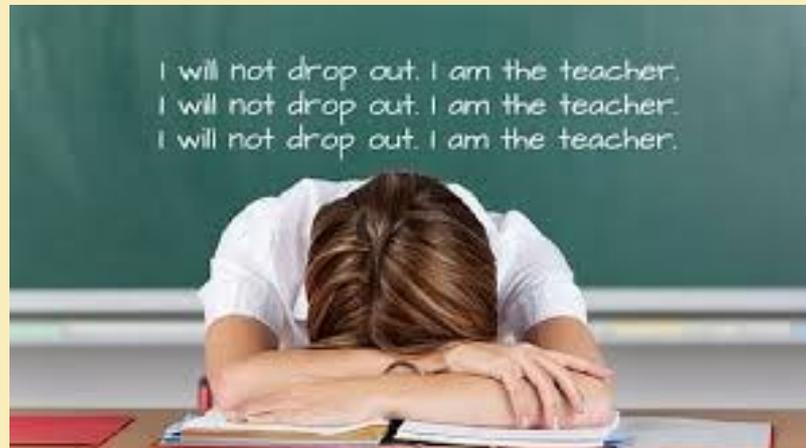


Image: melissabowers.com



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Session Outline

Review key principles of concordance in relation to non-medical prescribing.

Consider the potential value of working towards concordance with young people and their families.

Reflect on means of achieving concordance in prescribing for children and adolescents.



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The History (Bond, 2004)

1995 Marshall **Marinker** chairs RPS steering group examining extent, causes and consequences of non-compliance.

1997 **Partnership in Medicine Taking** - 'Anger and frustration of patients who felt infantilised by professionals with lofty intentions and unconvincing skills'.

Later 1997 '**From Compliance to Concordance: Shared Goals in Medicine Taking.**'



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What is Compliance?

‘Compliance is defined as the extent to which the patient follows the health professionals’ advice and takes the treatment’.

Cushing and Metcalfe, 2007



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What is Adherence?

‘The view that the informed (but still passive patient) will stick (adhere) to taking the recommended treatment.’

Marland et al, 2012



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Image: Dynamicballroomdancing.com

What is Concordance?

‘Agreement between the patient and healthcare professional, reached after negotiation that respects the beliefs and wishes of the patient in determining whether, when and how their medicine is taken, and (in which) the primacy of the patient’s decision (is recognized)’

Marinker cited by Cushing & Metcalfe, 2007



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More than Semantics?

Concordance relates to the process, outcomes and ethics of prescribing- **shared decision making**.

It is in danger of being understood as either a synonym for compliance or, at best, a behaviour change intervention aimed at achieving adherence.

Choice, self determination and empowerment can improve safety (Roy & Snowden, 2012)

‘A partnership of equals’!! (McKinnon, 2014)



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Forming Partnerships with Patients

‘Patient involvement in decision making is a specific example of an attitudinal shift in society towards greater individual autonomy and choice. With a shift of burden from acute to chronic disease in the population, the active and informed involvement of patients to prevent or manage their illnesses is desirable’.

Cushing and Metcalfe, 2007



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From Compliance to Recovery Orientated Practice

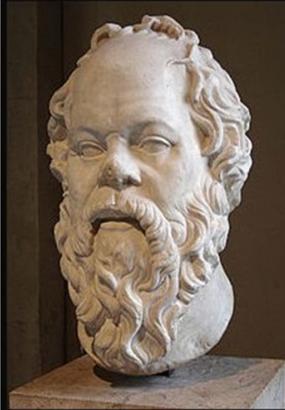
‘The processes of engagement and collaboration intrinsically promote self-esteem, ownership and commitment. The therapeutic alliance acknowledges the scientific and clinical expertise of the mental health worker, and the service user’s knowledge of his preferences and subjective experiences.’

Marland et al, 2012



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The children now love luxury, they have bad manners, contempt for authority, they show disrespect for elders and love chatter in place of exercise. Children are now tyrants, not the servants of their households. They no longer rise when elders enter the room. They contradict their parents, chatter before company, gobble up dainties at the table, cross their legs, and tyrannize over their teachers.

(Socrates)

izquotes.com



Is Concordance Relevant to Children and Young People?

Take your Medicine as Prescribed!

‘Bribe, tempt, trick, persuade, convince, sweet talk, explain and negotiate. I use all of these, in addition to sometimes forcing. It is my duty. I am the mother and have to decide’.

Bergene et al, 2017





Take your Medicine as Prescribed!

‘When I was younger, I didn’t have a whole lot of say in what was going on... It was just, “Take your medicine.” As I got older, they started talking to me more. ... **It got better as I got older**’

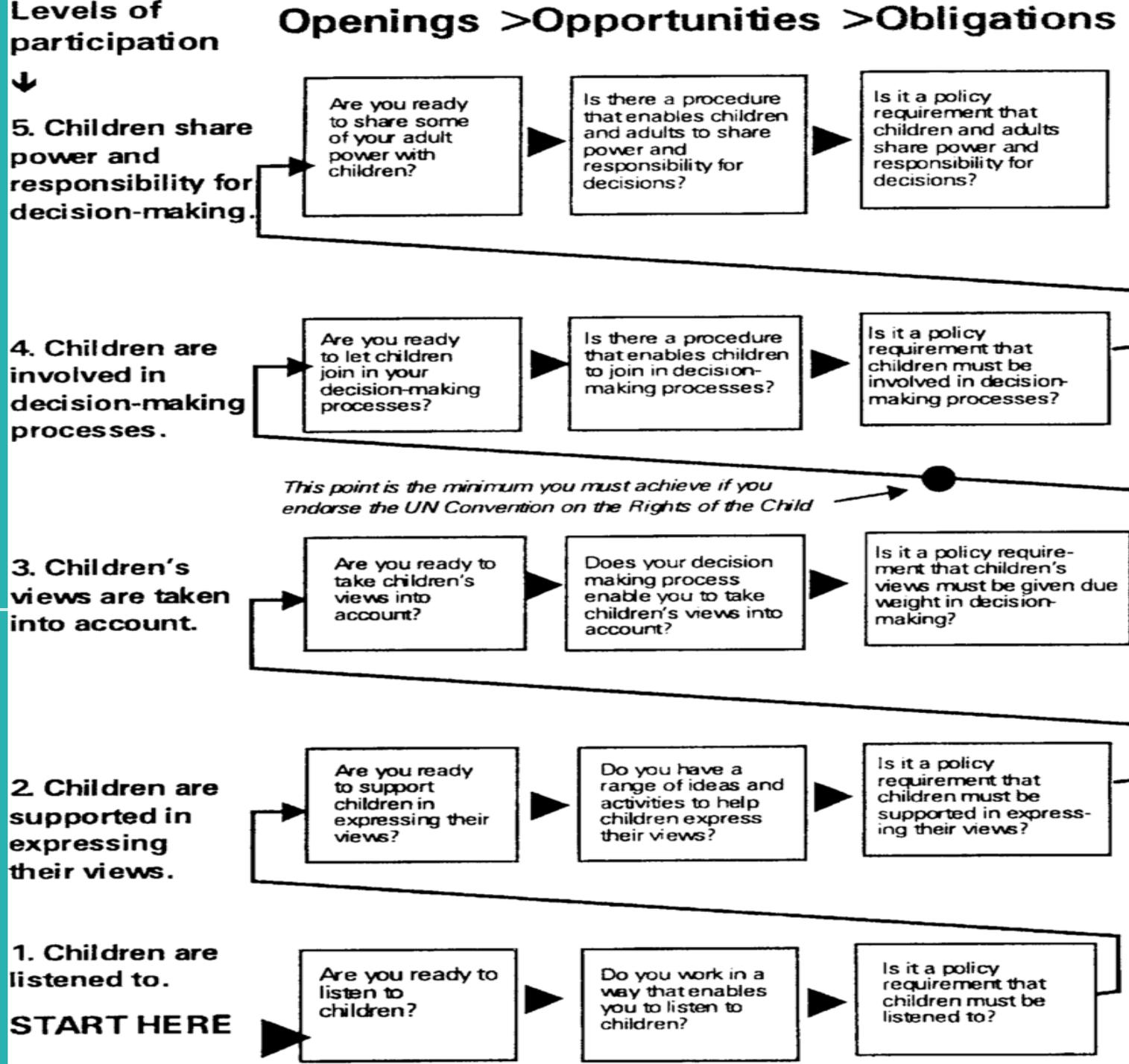
Rashid, 2018



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Shier's Model



Shier, 2001

-
8. Young people-initiated. Shared decisions with adults
 7. Young people-initiated and directed
 6. Adult-initiated. Shared decisions with young people
 5. Consulted and informed
 4. Assigned but informed
 3. Tokenism
 2. Decoration
 1. Manipulation
-



Hart's Ladder of Participation

Hart, 1992

Image: Me First



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He Doesn't Need to Know That!



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So what does he need to know?

Depends more on **what children would like to know** than on what we think they need to know.

In general children do want to know about their medicines.

Encourage questions- **teach children how to ask questions of NMP**

Basic information about use/ misuse of medication to be taught in school

Sanz, 2003



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Fear of Medication

Keep away!!

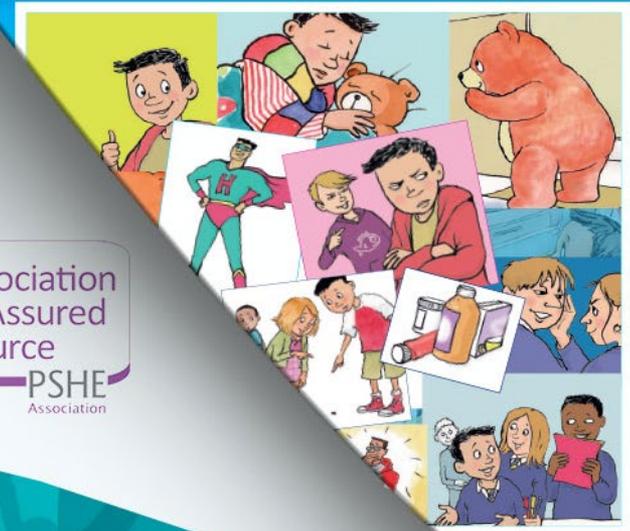
Dangerous!!

Potential for misinterpretations of adult conversations- and even PSHE. Check understanding.

De Maria et al, 2011

Jed & Ted Explore

Medicines, Alcohol, Tobacco & other Drugs



PSHE Association
Quality Assured
Resource

PSHE
Association

Skills

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Unanswered Questions!

Sleath et al, 2017

The average young person taking medication for ADHD has 8 unanswered questions

Having more questions was associated with poorer adherence and greater need for parental reminders

Most young people want their prescriber to engage with them more



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Barriers to asking Questions

Discomfort

Not knowing what to ask

The prescriber 'directs questions at my parents'

The prescriber 'talks too much' and 'doesn't ask me any questions.'

Sleath et al, 2017



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Working within Child-Parent-Clinician Triad



Image:Newsmedical.net



Image: CDC



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Concordant Relationship of Three (or Four!)

A triangular, child focused, partnership

Child focused but engaging with parent as expert on own child

Parent as mentor, interpreter, teacher

Clarifying and informing on child's perspective and wishes

McKinnon, 2014



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Concordant Relationship of Three (or Four!)

Child friendly books, leaflets, posters and apps. Use of games, toys, craft materials.

Concordance pathway within record- means of explaining medication with developmentally appropriate content

Care plans with dedicated space for child's views

Value parental role as intermediary. Explain heightened anxiety caused by lack of child involvement.

McKinnon, 2014



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Or More? Memories from Practice!

Interacting with Children around Medication

- Include children in conversations about their medication at a young age
- **Allow children to share their understanding about use of medicines using their own language**
- Describe medications- size/ colour- particularly under 10
- **Use term 'medicine' not drug**

De Maria et al, 2011



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Interacting with Children around Medication

- Screen for understanding of mechanism of action – **impacts adherence**
- Discuss **both therapeutic and side effects** with children
- If forgetting is problematic, work together on methods to keep track of medicines taking

De Maria et al, 2011



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What do we need to know?

The child's perceptions and understanding of the impact of being medicated on lifestyle, achievement and self concept.

Children tend not to see stimulant medication as a threat to authenticity/ agency

Advocates reflective relational, collaborative stance seeing child as capable of reason and worthy of respect

Prescribers fulfil their role of 'gatekeeper'

Singh, 2012



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What do we need to know?

Trivedi (2017) reminds pharmacists to ‘consider the **vital role of children** in medicines optimisation’.

‘Paying attention’ to young person’s feelings and concerns

‘Partnership building’ – inviting expression of concerns and suggestions – understanding young person's perspective.

‘Information giving.’

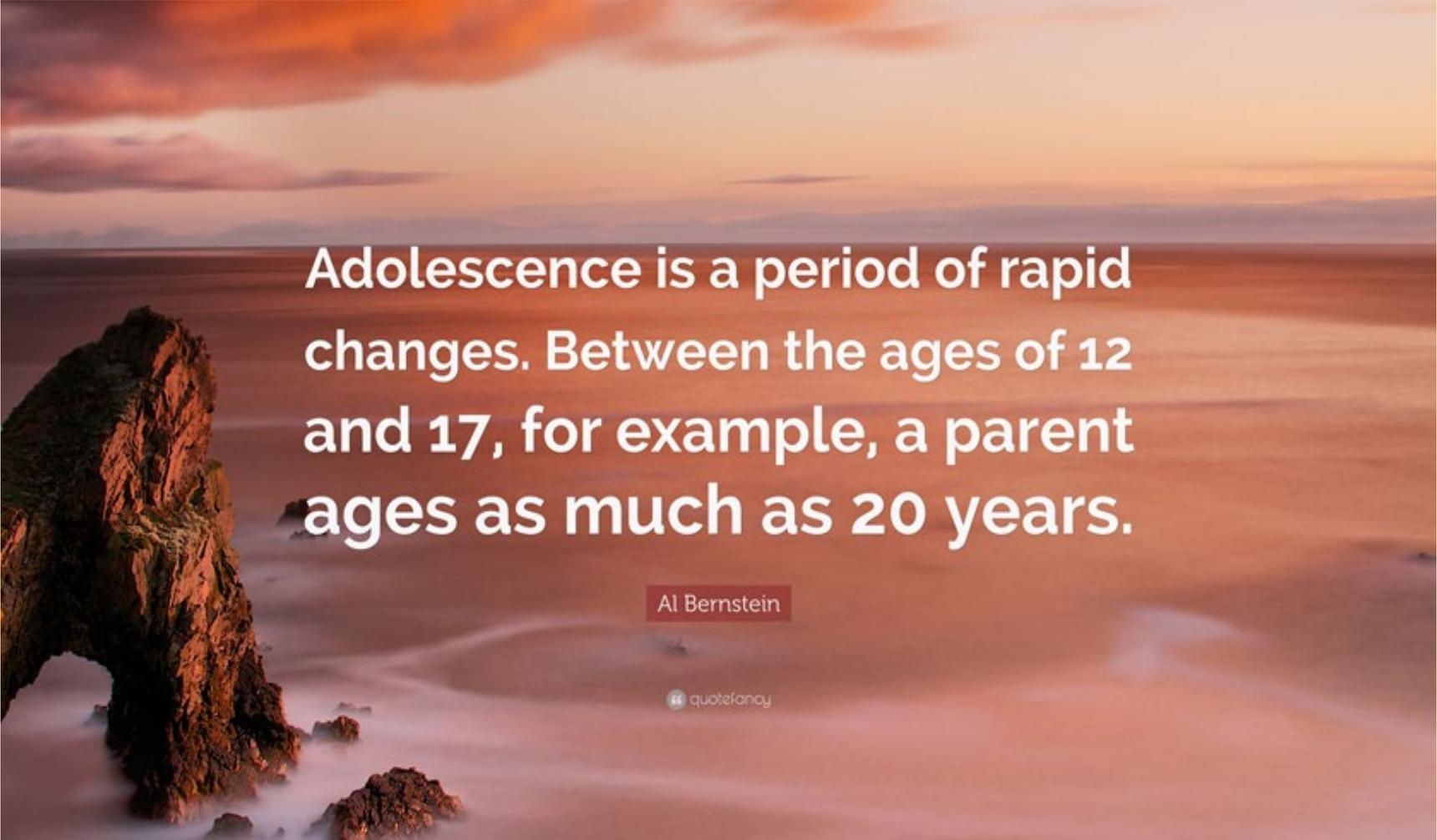


Image: Cultura Creative in Trivedi (2017)



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Adolescence is a period of rapid changes. Between the ages of 12 and 17, for example, a parent ages as much as 20 years.

Al Bernstein

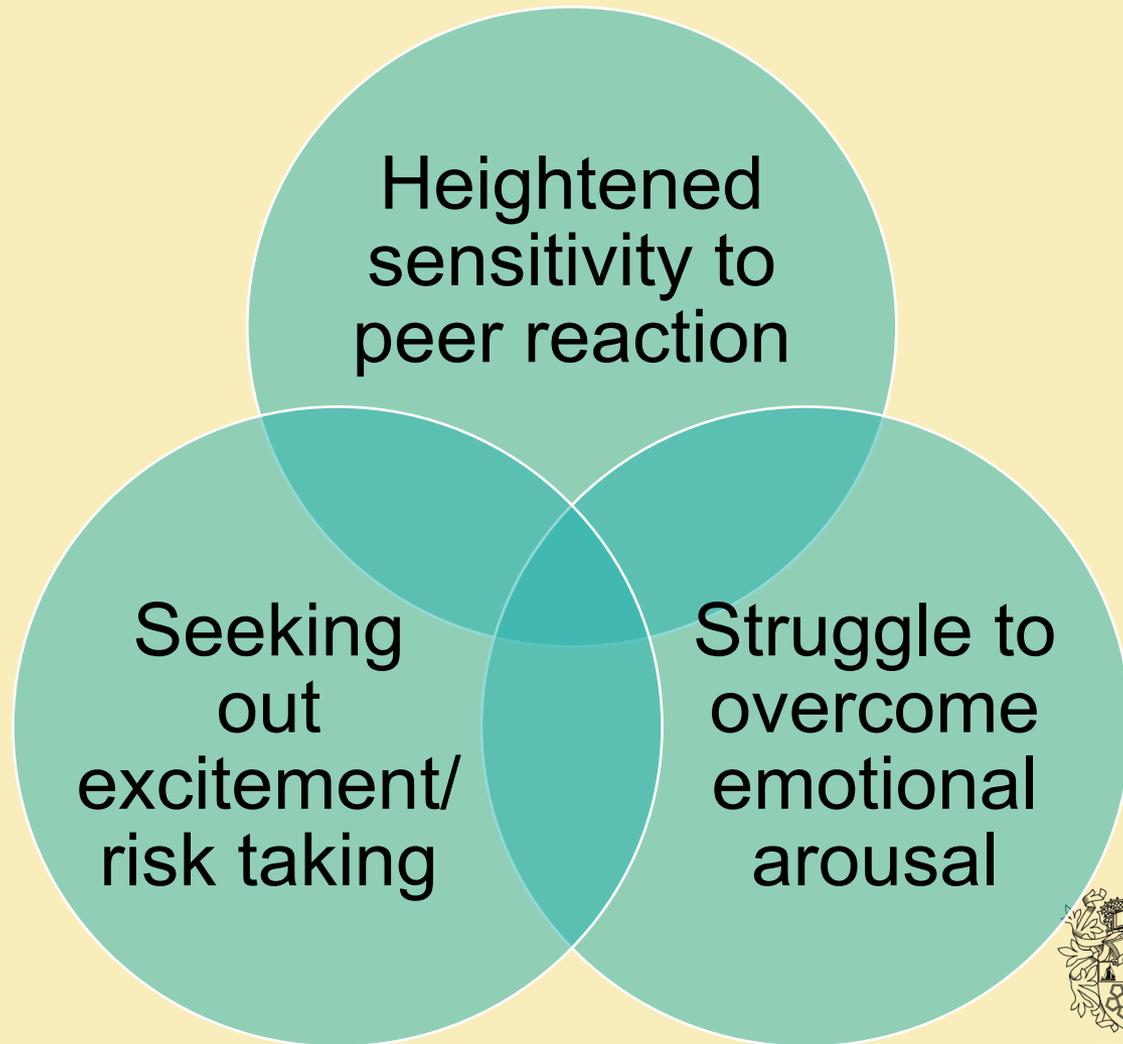
quote fancy



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The impact of adolescence



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Take your Medicine as Prescribed!

'If you don't take your medication you won't get the grades you need.'



Image: more-love.org

'It's worth putting up with a few side effects to get a university place'.

'If you don't take this medication you will end up being excluded'.



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Factors Influencing Adherence

Difficulties with self reflection

Difficulties with decision making

Emotional Lability

Seeking autonomy and immediate reinforcement.

Difficulties with Planning and Organisation.

Sensitive to Stigma



Factors Influencing Adherence

Self esteem linked with greater adherence

Effectiveness, tolerability and dosing

Therapeutic alliance

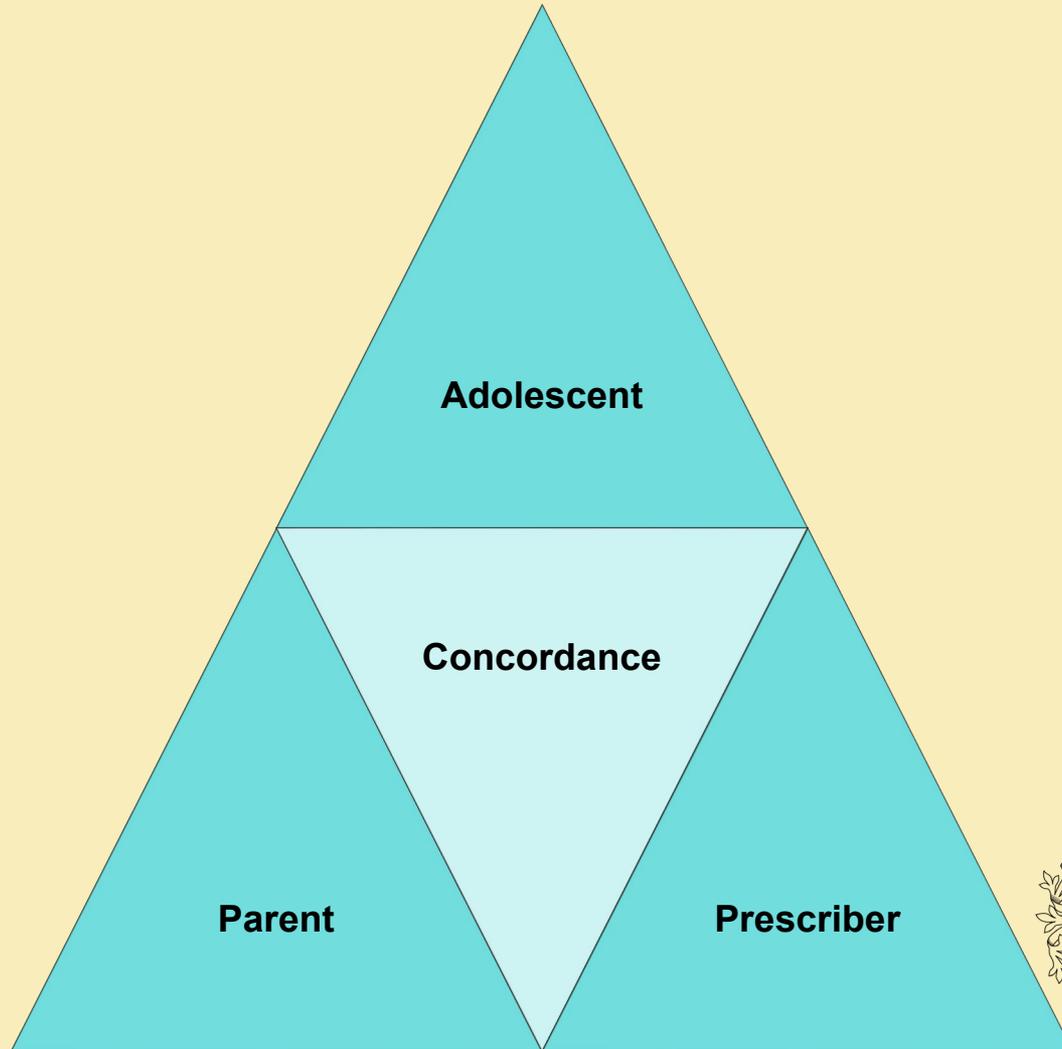
Health beliefs and perceptions about the disorder, attitudes toward medication

Surrounding social system (families and friends,

Illness theories and experiences



Shifting Power Dynamics



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Self Reported Barriers

Relationship to peers and parents plays a crucial role
Sense of 'normality' in relation to construction of identity

Desire to be 'normal'- 'Not fair'

Emphasis on 'wanting to forget' illness (difference)

Notes need to seek adolescents own views on
interventions supporting adherence.

Hanghoj & Boisen (2014)



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Self Reported Barriers

Poor communication- lack of support- lack of information from prescribers-

‘desire for freedom’ (v feeling controlled)

Side effects

Forgetting

Doubting Usefulness.

Hanghoj & Boisen (2014)



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Working towards Concordance

Support the young person by working with awareness of growing external influences on decisions about medicines taking

Helping young person to find and articulate a **personal set of 'trade offs'**

Maintain awareness of (and support) a gradual shift towards young person as primary decision maker.

Rashid et al, 2018



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Take Away Points

Do not under-estimate:

- the potential of children and adolescents to understand their medicines, or
- the longer term value in them doing so in terms of agency and understanding.

Obtain a full understanding of what medicines taking means for the young person in their context. (–Psychosocial assessment across settings).

Do not give up on achieving a concordant relationship with any patient who does not yet have autonomy.



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