Communication, language and speech in PMS

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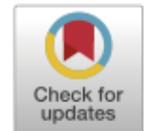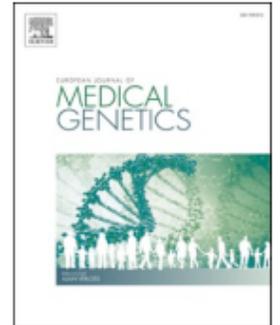
Consensus recommendations on communication, language and speech in Phelan-McDermid syndrome

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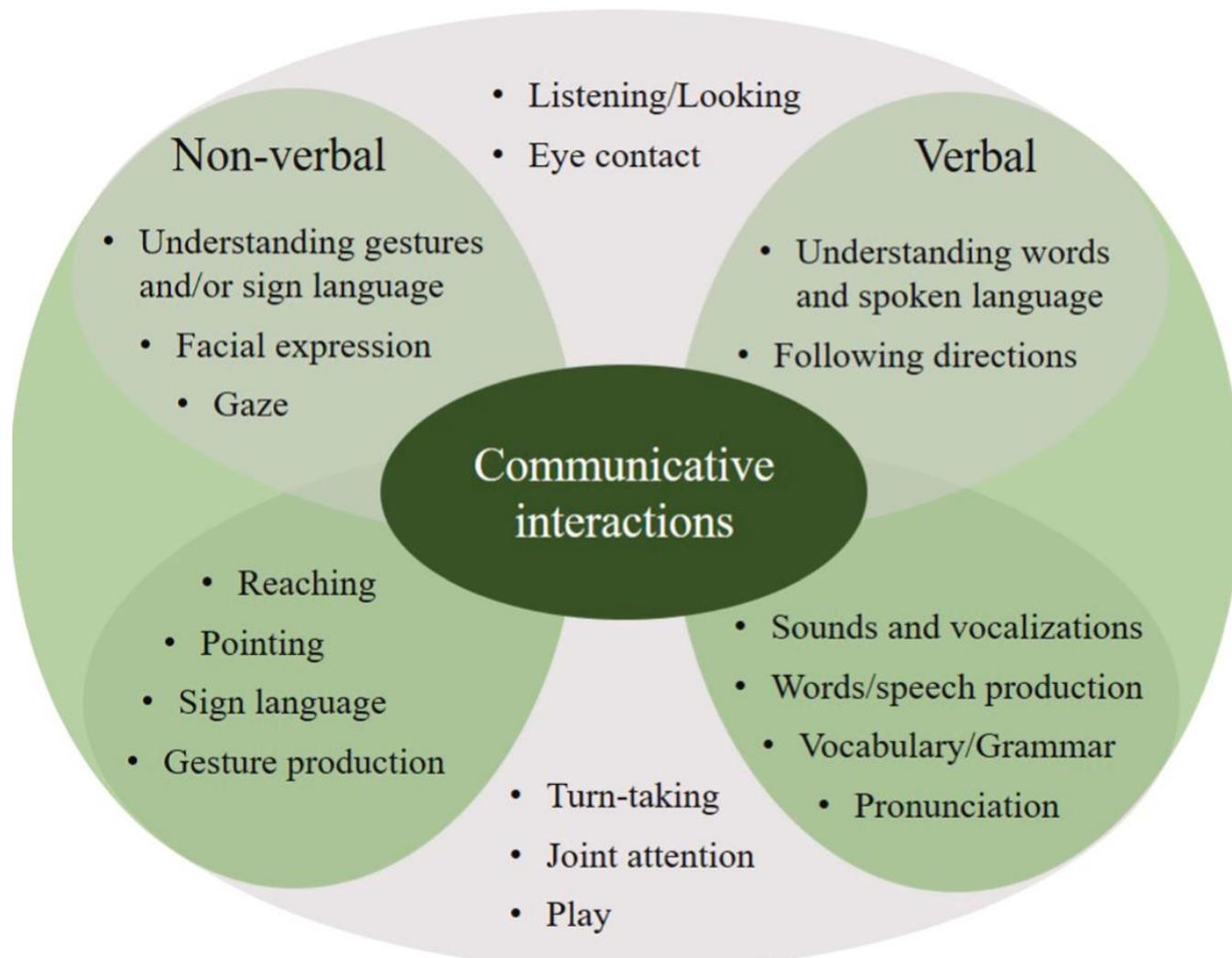
Communication, language and speech are particularly affected in PMS. Different presentations can occur: problems with acquiring language, articulation or pronunciation, or absent speech and impaired ability to communicate, either verbally or non-verbally.

The limitations in communication are one of the most common concerns of parents.

Communication, language and speech in PMS

Clinical features	PMS individuals with 22q13.3 deletion (%)	PMS individuals with *SHANK3* variant (%)
Global developmental delay/ID	95-100	85-100
Marked speech impairment	85-90	60-80
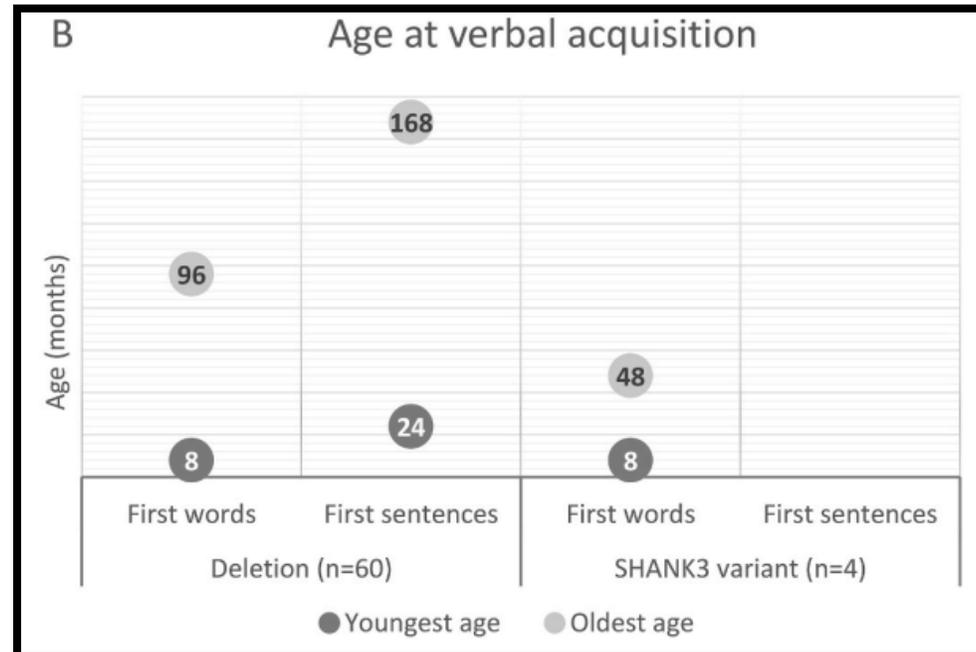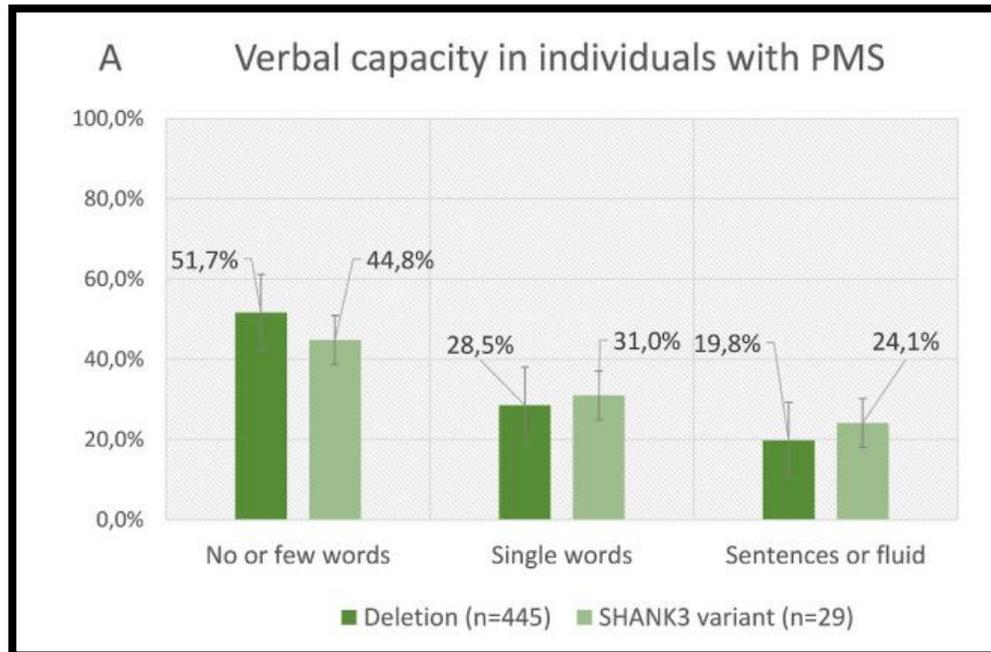
Communication, language and speech in PMS

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Given the high frequency and severity of communication problems in individuals with PMS, it is important a) to understand possible associated factors, and b) to start from the question: **"What does the individual with PMS needs to be able to (better) communicate?"**

@the assessment
@the intervention

Possible factors associated with CSLP in PMS

POSSIBLE INFLUENCING FACTORS

Genetic:
- Origin of condition (deletion vs. variant)
- Size/locus
- Additional genetic rearrangements
- ...

Developmental/behavioural:
- Intellectual disability
- Psychiatric issues
- Developmental regression
- ...

Environmental:
- Socioeconomic status
- Parental stress
- Dyadic interaction style
- Intervention
- ...

Medical/somatic:
- Conductive/hearing problems
- Hypotonia and poor muscle strength
- Seizures
- ...

Communication, language and speech in PMS

Development / life stage

Recommendations and possible treatments for communication, language and speech problems in PMS

- Hearing should be checked at the time of diagnosis and regularly thereafter to detect possible hearing loss.

- A specialized multidisciplinary team should evaluate all factors that may influence communication, speech and language. *This includes for example, hearing, cognition, oral motor coordination, palate function.*

- Preverbal and verbal communicative skills and cognitive development should be evaluated prior to speech therapy and other interventions, *because the individual should be addressed at the appropriate cognitive level. One should also be aware that the individual may need more time to process information.*

  - There is a free online tool to map communicative skills of people with severe or multiple disabilities called "Communication Matrix". It helps families and professionals to understand the communication status, progress and needs of individuals that use other communication forms besides speaking or writing. https://www.communicationmatrix.org/

Recommendations and possible treatments for communication, language and speech problems in PMS

- Parents should be instructed and supported by a specialist on supporting, facilitating, and stimulating communication, language and speech from an early age on. *This may include talking slowly, articulated and face-to-face.*

- Preverbal therapy is recommended that focuses on oral motor skills or supported communication in the form of photos, objects, gestures, pictograms, or a communication device with speech output.

- The use of communication aids is recommended to facilitate communication for individuals with PMS. These aids do not delay the active language development. *Examples are speaking with gesture support, speech computers and other tools.*

- At a later stage, if the communicative development of the child permits, attention can shift to receptive and/or expressive language.

Total communication/communication aids

Photos

Objects

Picto's

t-shirt

uitkleden

aankleden
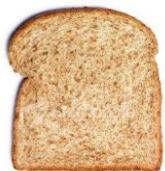
Gestures
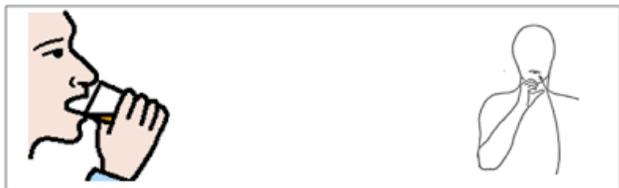
PCS
symbols

Eat   More   Why?
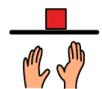
When?   Want   Go

......

Communicatie

Leren communiceren

Starters

Plaatjessystemen

Tekstsystemen

Dynamische systemen

Software

Vocabulaires

Spraaksynthese

Overige

HULPMIDDELEN

Communicatiehulpmiddelen

Leren communiceren

Starters

Plaatjessystemen

Tekstsystemen

Dynamische systemen

Software

Vocabulaires

Spraaksynthese

Overige

Bedieningshulpmiddelen

Omgevingsbediening

Zelfstandig leven

Spel en therapie

Adaptatietechniek

Neem contact op!

Heeft u vragen of opmerkingen?
Wij horen het graag!

Neem contact met ons op

Alternative/augmentative communication systems (AACS)

https://www.jabbla.com/en/

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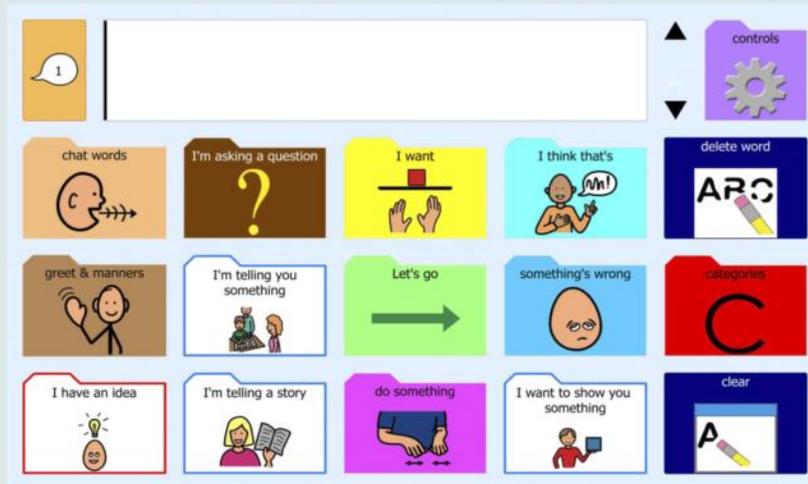
Mind Express communication software

Our communication software Mind Express helps children, adolescents and adults who cannot speak. Mind Express allows people to say out loud what they are thinking or feeling. Use the software for daily chats, to learn and expand language. Remote communication is also easy, for example via e-mail, text messages and WhatsApp. Or use environmental control, such as turning on the television, opening the door, switching on the light ... Mind Express is communication software in the broadest sense.

DISCOVER MIND EXPRESS ›

Alternative/augmentative communication systems (AACS)

https://www.jabbla.com/en/

Accessible communication device

Everyone has their talents and limitations. A touch screen, for example, is not suitable for everyone. That is why you can customize our communication devices. Access the AAC device with hands or fingers (touch screen, joystick and switches), with the head (head tracking) or with the eyes (eye tracking). Look into which communication device suits your needs. A large communication device on which you can see everything clearly from a wheelchair? Or rather a compact companion?

WHICH COMMUNICATION DEVICE SUITS YOU BEST? >
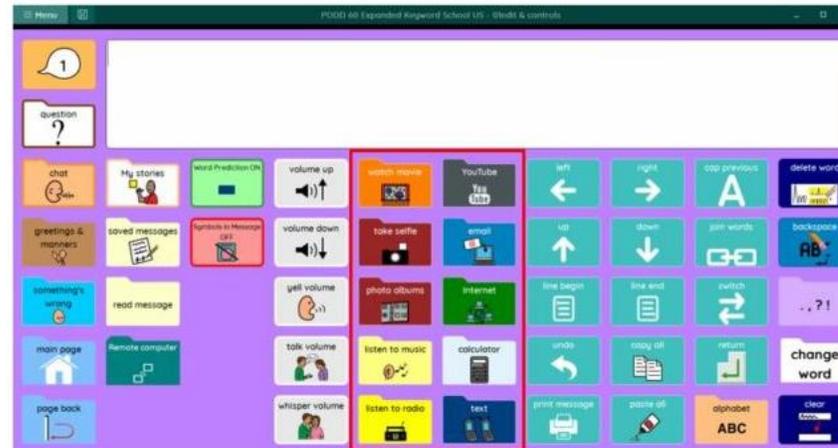
Ready-made vocabulary

Communication page sets are constantly evolving. Although you can always add words and themes, sometimes you have the feeling that you are running behind the facts. After your day trip, for example, it turns out that the word of the day was missing: ice cream. This is one of the reasons to try out ready-made vocabulary. They are comprehensive and logically constructed from scientific and practical insights.

WHY CHOOSE A READY-MADE VOCABULARY? >

Alternative/augmentative communication systems (AACS)

https://thinksmartbox.com/product/grid-3/

Conclusion

Thank you for your attention!

Walk hand in hand
with their physicians and caregivers
towards a brighter future