

Report Supplementary Material File 5

Excerpt from a Padlet used during analysis meeting

Mayara Silveira + 2 • 9mo
CHAMPION

- Importance of diagnosis [for parents]**
[Brodwall#5239, Smart#3799]_AP_3rd oc
- Parents/mother [feel like they] have to recognise and manage child's pain [by using intuition/sense of knowing]**
[Brodwall#5239, Smart#3799]_AP_3rd oc
- The complexity of [accessing and accepting] psychosocial support [parents]**
[Brodwall#5239, Smart#3799]_AP_3rd oc
- Parents and YP - loss of normality [or loss of a normal life and childhood]**
[Macivier#3873, Macivier#3872, Dell'Api#5023, Jordan#4868, Suder#3299, Sorensen#3384]_MIX_3rd oc
- Medical encounters - the importance of communication [being listened to and believed]**
[Carter#5756, Macivier#3873, Macivier#3870, Carter#5752, Dell'Api#5023, Suder#3299, Baert#5871]_MIX_3rd oc
- Parents managing pain & making difficult decisions about this alone**
(NC_Carter#5751, Hunt#5994, Carter#5754)_NC_3rd oc
- Self-management of painful episodes (adolescents)**
[Atkin 6047, Atkin 6046, Renedo#3628]_SCD_3rd oc
- Trying to achieve a 'new normality'**
(Britton#5240, Rosatto#3590, Waite-Jones#6068, Guell #4729, Cartwright#5749)_JIA_3rd oc
- Parents' interaction/relationship with HCP and desired outcomes**
[Brodwall#5239, Smart#3799]_AP_3rd oc
- Perception of psychologist affects how families experience services [stigma and/or last resort treatment]**
[Carter#5756, Macivier#3873, Sorensen#3384, Macivier#3870]_MIX_3rd oc
- Pain affects social role of YP [with family, friends and peers]**
(Forgeron, Khanom, Ahlqwist)_MSK_3rd oc
- YP's desire to live a normal life challenged by all aspects associated with CP [which causes feelings of powerlessness and frustration]**
(Forgeron, Khanom, Ahlqwist)_MSK_3rd oc
- Parents as healthcare advocates**
(Carter#5751, Carter#5754)_NC_3rd oc
- Biomedical perspective of pain a barrier to effective treatment, biopsychosocial perspective is a facilitator/ the need for holistic biopsychosocial care**
(UN_Nutkiewicz#4196; UN_Kanstrup#4847)_UN_3rd oc
- Mothers feel responsible for child health & feel judged by HCPs**
[Brodwall#5239, Smart#3799] (possible 3rd order construct)_AP_3rd oc
- Positive & negative impacts on siblings**
(Britton#5240, Waite-Jones#6068)_JIA_3rd oc
- Ambivalent family relationships [CYP and parents]**
[Atkin 6046, Njifon#4213, Atoui#5591]_SCD_3rd oc
- Parents value validation from HCPs**
(Castle#5740, Hunt#5994)_NC_3rd oc
- Parents' biomedical versus psychosocial orientation**
[Brodwall#5239, Smart#3799]_AP_3rd oc
- Pain affects/impact parents physically and emotionally**
[Macivier#3873, Macivier#3872, Jordan#6296]_MIX_3rd oc
- Chronic pain makes the future uncertain [CYP and parents]**
[Gaughan #4903, Jones#4883]_CRPS_3rd oc
- Pain negatively affects YP's self-identity**
(stigma, lower self-esteem, feel abnormal but want to be treated as normal) (Forgeron, Khanom, Ahlqwist)_MSK_3rd oc
- YP's strategies to restore 'control' of daily-life and pain**
(Forgeron, Khanom, Ahlqwist)_MSK_3rd oc
- Painners' expert & intuitive/subjective**
- JIA & its management dominates [& strains] family life & changes**
- Knowing right illness vocabulary gives parents more control/ power in medical world**
- [Parents] seek information**
[Macivier#3873]_OC