Perception towards Psychological Flexibility Treatment by the Parents of Young People with Chronic Pain

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BACKGROUND

Chronic pain in young people leads to suffering of the individual and also the family members. Acceptance and Commitment Therapy (ACT) is a form of psychological treatment targeting Psychological Flexibility (PF) which have been found to be effective for young chronic pain patients (McCracken & Morley, 2014; McCracken & Gauntlett-Gibert, 2011). In a recently published guidelines by the World Health Organization (2020), cognitive behavioural and related interventions including ACT were included as the strongest recommendation for chronic pain in children. However, there has been relatively less studies in concluding the state of ACT work conducted with young people together with their parents. Prior to developing a treatment protocol that fits well into the Malaysian context, this survey study aims to explore parents' perception towards the intervention for themselves and their children with chronic pain.

| Demographics | N (%) / M (SD) |
|-------------------------------------|----------------|
| Parent's age | 47.54 (5.37) |
| Child's age | 14.42 (2.40) |
| Parents | |
| Father | 5 (10.4) |
| Mother | 43 (89.6) |
| Ethnicity | |
| Malay | 13 (27.1) |
| Chinese | 22 (45.8) |
| Indian | 10 (20.8) |
| Others | 3 (6.3) |
| Child's pain diagnosis | |
| Systemic Lupus Erythematous (SLE) | 8 (16.7) |
| Chest pain | 7 (14.6) |
| Rheumatoid Arthritis | 6 (12.5) |
| Juvenile idiopathic arthritis (JIA) | 5 (10.4) |
| Migraine | 4 (8.3) |
| Abdominal pain | 4 (8.3) |
| Cerebral Palsy | 2 (4.2) |
| Waist pain | 2 (4.2) |
| Chronic pain | 2 (4.2) |
| Fibromyalgia | 1 (2.1) |
| Nerve sensitization hypermobile | 1 (2.1) |
| No diagnosis | 6 (12.5) |

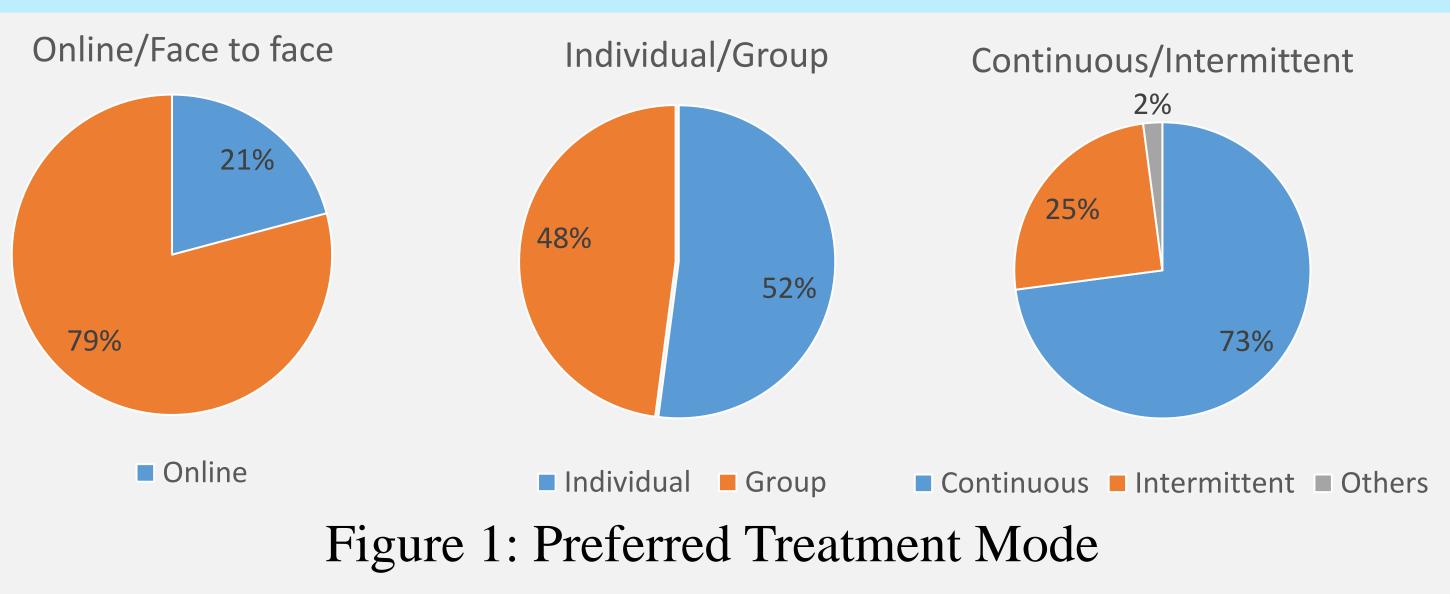
Table 1. Demographics of participants

METHOD

Fifty-two Malaysian parents of young people (11-18 years old) with chronic pain condition were recruited online via purposeful sampling from social media to complete a web-based questionnaire. Demographic information such as parent and child's age, ethnicity, child's pain diagnosis and duration of pain was recorded. A short version of Brief Pain Inventory (BPI), which consists of a 9 items, was completed by parents to report on the severity of children's pain and the impact of this pain on the daily functioning.

Next, the questionnaire provided brief descriptions about ACT and PF and asked parents to rate their preferences of treatment modes (e.g., face to face or online, group or individuals, continuous or intermittent, short or long duration). Five-point rating scales (e.g., 0=not effective at all, 4=very effective) were included to assess parent's belief on the effectiveness of the proposed program, and motivations and barriers to attend such a program. Participants were also allowed to give qualitative responses with optional open-ended questions.

In terms of preferred mode of treatment, descriptive analysis showed that parents preferred face to face compared to online method, individual session compared to group session, and continuous compared to intermittent session. Figure 1 illustrates the percentage of parents' preference on treatment mode.



RESULTS

A total of 48 participants who fulfilled the inclusion criteria were included in the analysis after data cleaning (i.e., excluded participants whom child's age were above 18 years old or the pain condition experienced did not last for at least 3 months). The results showed that 89.6% of respondents are mother and the rest are father. The duration of children's pain condition ranged from 3 months to 192 months with an average of around 23 months (SD=39.77).

Based on the BPI, the average pain score was 4.25 (SD=1.16) out of 10. In the scale of 0 (does not interfere) to 10 (completely interferes), the

With regard to participants' belief in the effectiveness of program, majority of participants believed that the treatment would be effective, with 62.6% of parent gave a rating of 3 or 4 out of 4. A high percentage (91.7%) reported that they are motivated to attend the program with the intention to help their child as the most commonly stated reason (31.3%). With regard to the barriers, 18.8% reported the reason of not having heard about the treatment and 16.7% reported being unsure about the effectiveness of the program.

DISCUSSION & CONCLUSION

The current sample suggests that parents of children with chronic pain conditions are motivated and open to ACT based intervention targeting PF, with preference on individual face-to-face sessions that are conducted continuously. The findings also suggest the importance of public dissemination on ACT as an effective treatment for young people with chronic pain and their parents to reduce the barriers to treatment. This self-report study can be further improved by including more participants and interviewing the children with chronic pain.

participants reported that the pain has moderately interfered their child's general activity (M=5.58, SD=2.18), mood (M=6.85, SD=2.00), walking ability (M=4.88, SD=2.76), normal work (M= 4.90, SD=2.15), relationship with people (M=4.15, SD=2.06), sleep (M=6.29, SD=1.99), and enjoyment in life (M=6.98, SD=2.18). Table 1 shows the details of demographics and the child's pain diagnosis.

In conclusion, in view of the positive attitude and perception from parents, there is support that an ACT treatment protocol tailored to Malaysian young chronic pain patients and their parents should be developed and tested.

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