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

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ABSTRACT: Chronic pain in young people leads to the suffering of the individual and their family members. It has become a significant concern as it causes negative consequences for adolescents. A questionnaire study was conducted to better understand parental attitudes toward such intervention for themselves and their chronic pain children. The study aims to understand parental perception towards such intervention for themselves and their children with chronic pain. This study is in line with the "Pain as the 5th Vital Sign" program promoted by the Malaysian Ministry of Health in 2008 to ensure that patients' pain is effectively managed. Parents were recruited via purposeful sampling and completed a web-based questionnaire. The questionnaire consisted of brief descriptions of ACT for chronic pain and asked parents to rate their preferences for treatment modes, perception of the effectiveness of the program, and their motivation and barriers to joining the proposed program. Descriptive analysis of 48 participants showed that parents preferred face-to-face (79.2%) compared to the online method (20.8%), individual sessions (52.1%) compared to group sessions (47.9%), and continuous (72.9%) compared to intermittent (25%) sessions. Most participants (62.6%) believed the treatment would be effective. A high percentage (91.7%) of participants reported being motivated to attend the program. The findings contribute to the lack of studies dealing with intervention for adolescents suffering from chronic pain in Malaysia. This study suggests that Malaysian parents of children with chronic pain conditions are open to ACT intervention targeting psychological flexibility and a contextualized treatment protocol should be developed and tested.

Keywords: Acceptance and commitment therapy (ACT), chronic pain, psychological flexibility, young people

INTRODUCTION

Pain is regularly experienced by children and adolescents (Tutelman et al., 2021). Although no exact data is available in Malaysia, it is believed that 5% of young people there suffer from severe chronic pain and require pain medication (Stahlschmidt, 2019). Teenagers' chronic pain has become a severe worry due to its harmful effects on them (Kashikar-Zuck, 2020; Murray et al., 2019; Haraldstad et al., 2017). Chronic pain often leads to avoidance of daily activities due to fear that activities will worsen the pain (Nordstoga et al., 2019). However, avoiding chronic discomfort will result in more impairments (Crombez et al., 2012). The primary therapeutic component of chronic pain in Acceptance and Commitment Therapy (ACT) is psychological flexibility (PF) (Lin et al., 2017). In the context of chronic pain, the core PF components, which include avoidance reduction, awareness enhancement, and behavioral engagement, are beneficial to increasing people's functioning in their daily lives (Feliu-Soler et al., 2018). Additionally, the World Health Organization released a guideline for treating chronic pain in young people.

The strongest recommendations for treatments for children's chronic pain were stated in the guidelines, which include cognitive behavioral therapy and related interventions, such as ACT, behavioral therapy, and relaxation therapy. Furthermore,

these recommendations outweigh the use of medical treatment (WHO, 2020). In pediatric chronic pain management, the role of the caregiving parent is described as a critical but neglected aspect (Russell et al., 2020). In recent years, preliminary evidence on the benefit of including parents in the treatment of pain conditions in young people has been indicated (Poppert Cordts et al., 2019; Weiss et al., 2019; Kemani et al., 2018). However, the systemic effect of caregivers on facilitating self-management transition for adolescents with chronic conditions is still not well understood (Stahlschmidt & Rosenkranz, 2020). Overall, there is a scarcity of literature focusing on ACT work in children and their parents. The involvement of parents in pediatric chronic pain management is regarded as a crucial but neglected part (Russell et al., 2020). Preliminary research on the advantages of involving parents in treating young people with pain issues has emerged in recent years (Poppert Cordts et al., 2019; Weiss et al., 2019; Kemani et al., 2018). However, the systemic effect of caregivers in assisting self-management transition for adolescents with chronic conditions is still yet to be fully understood. Overall, limited literature focuses on ACT work as a kind of treatment for young people and their parents. Prior to developing a treatment protocol that fits well into the Malaysian context, this study aims to understand parental perception towards PF intervention for themselves and their children with chronic pain. This research supports the "Pain as the Fifth Vital Sign" program, which the Malaysian Ministry of Health supported in 2008 to ensure that patients' pain is properly managed. The purpose of the study is to understand parental perception towards such an intervention for themselves and their children with chronic pain and the feasibility of the intervention.

MATERIALS/SUBJECTS AND METHODS

Sample and location

A total of 52 Malaysian parents of young people with pain problems were recruited through online social media via a purposeful sampling method. The inclusion criteria of participants include: (i) Participants must be Malaysian. (ii) Participants need to be parents of adolescents (11-18 years old) with chronic pain (at least 3 months duration).

Procedure

Participants completed a web-based questionnaire. Demographic information such as parent and child's age, ethnicity, child's pain diagnosis, and duration of pain was recorded. The Brief Pain Inventory (BPI) was also administered in a short version. Participants were asked to rate their child's worst, least, average, and current pain intensity; current treatment, perceived effectiveness of current treatment; and the degree that pain interferes with general activity, mood, walking ability, normal work, relations with other people, sleep, and enjoyment of life on a 10-point scale. Next, the questionnaire provided brief descriptions of ACT and PF and asked parents to select their preferences for treatment modes (e.g., face-to-face or online, group or individuals, continuous or intermittent). Five-point rating scales (e.g., 0=not effective at all, 4=very effective) were included to assess parents' beliefs on the effectiveness of the proposed program and their motivations and barriers to attending such a program. Participants were also allowed to give qualitative responses with optional open-ended questions. The primary analyses of the study were focused on description analysis and preferences of treatment modes (e.g., treatment mode, motivation and barriers, and participant acceptability). The Statistical Package for Social Science (SPSS) 20th version has been chosen to analyze the data.

RESULTS

Only 48 participants who fulfilled the inclusion criteria were included in the analysis after data cleaning. Other participants who did not fulfill the inclusion criteria were excluded, such as their child's age is above 18 years old or the pain condition experienced did not last for at least 3 months.

Demographic profile of respondents

The results showed that 89.6% of respondents are mothers and the rest are the 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. On a scale of 0 (does not interfere) to 10 (completely interferes), the participants reported that the pain has moderately interfered with 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.

Table 1: Patient demographics (n = 48)

Variables		N (%)/M (SD)
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)
Parent's age		47.54 (5.37)
Child's age		14.42 (2.40)
Pain diagnosis	Rheumatoid Arthritis	6 (12.5)
	Migraine	4 (8.3)
	Cerebral palsy	2 (4.2)
	Nerve sensitisation hypermobile	1 (2.1)
	Abdominal pain	4 (8.3)
	Chest pain	7 (14.6)
	Waist pain	2 (4.2)
	Systematic Lupus Erythematous (SLE)	8 (16.7)
	Fibromyalgia	1 (2.1)
	Chronic pain	2 (4.2)
	Juvenile idiopathic arthritis	5 (10.4)
	No diagnosis	6 (12.5)

The type of treatment the participants sought was also recorded. A total of 47.9% of their children are using medication, 14.6% visit doctors, 18.7% do nothing about it, 8.3% seek psychotherapy, 4.2% go to physiotherapy, 2.1% use traditional medicine, and 4.2% combine physiotherapist and medication. However, most children were reported to experience 30% pain relief after receiving treatment, followed by 20% pain relief, 40% pain relief, and 50% pain relief. Only a few reported 10% of relief followed by 90% and 100% of pain relief. Only one reported pain relief of 70%, 80%, or no relief after treatments.

Preferred treatment mode

In terms of preferred mode of treatment, descriptive analysis shows that parents preferred face-to-face to online methods, individual sessions to group sessions, and continuous to intermittent sessions. Figure 1 illustrates the percentage of parents' preferences for treatment mode.

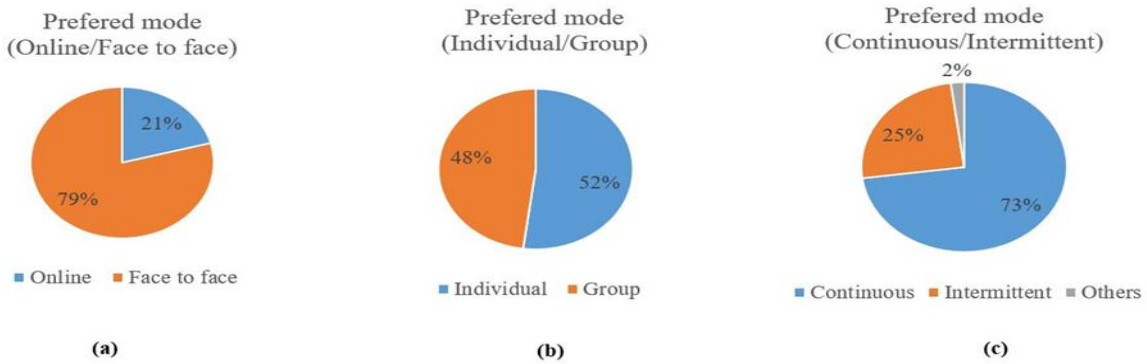

Figure 1: Parents' preference on treatment mode on (a) online/face to face, (b) individual/group (c) continuous/intermittent

Belief in the effectiveness of the program, motivation, barrier to attending the program

With regard to participants' belief in the effectiveness of the program, the majority of participants believed that the treatment would be effective, with 62.6% of parents giving a rating of 3 or 4 out of 4. A high percentage of 91.7% reported being motivated to attend the program. The qualitative reasons provided for the motivation or barrier to attending the program by

parents were analyzed. More than half of the participants (62.6%) reported wanting to help their child recover or reduce their child's pain. Other reasons given include a desire to try (12.5%), a strong desire to learn (2.1%), and a desire to learn (4.2%). Next, some barriers included child's rejection (4.2%), location issues (6.3%), expenses (2.1%), parents' physical illness (2.1%), or no support (4.2%). Details of the results are shown in Table 2.

Table 2: Reason of motivation or barrier to attending the program

Reasons	**N (%)**
I want my child to get better/recovery	24 (50.1)
Expenses	1 (2.1)
Parent's physical illness	1 (2.1)
Want to gain knowledge	2 (4.2)
I want to reduce my child's pain	6 (12.5)
Location	3 (6.3)
Child's rejection	2 (4.2)
No support	2 (4.2)
Very motivated	1 (2.1)
Want to try	6 (12.5)
Total	48 100.0

DISCUSSION

The current study aims to understand parental perception towards ACT intervention for themselves and their children with chronic pain to develop a treatment protocol that fits well into the Malaysian context. This study examined the child's pain diagnosis, average pain score, type of treatment received parent's preferred treatment mode and parent's belief in the program's effectiveness, motivation, and barriers to attending the program. With regard to the attitudes towards the point of ACT intervention, these findings suggest that parents of children with chronic pain conditions are motivated and open to ACT-based intervention targeting PF, with a preference for individual face-to-face sessions that are conducted continuously. Furthermore, the results showed that more than half of the parents believe that the ACT treatment is effective and are motivated to try it. This result is consistent with the findings that ACT treatment had been helpful for pediatric chronic pain and their parents (Kanstrup et al., 2019; Poddar et al., 2015). In addition, ACT treatment has improved the handling of individuals with chronic pain (Jenaabadi & Hosseini, 2020; Pielech et al., 2017; Vowles & McCracken, 2008). However, some parents are not confident with the treatment as they did not hear about it, were not sure about its effectiveness, and did not try it before. The findings suggest the importance of public dissemination of ACT as an effective treatment for young people with chronic pain and their parents to reduce the barriers to treatment. Based on the results, the findings suggest that Malaysian parents preferred face-to-face therapy sessions compared to online methods. The findings are similar to other survey studies in which most primary healthcare patients are interested in face-to-face interventions compared to online treatment (Berle et al., 2014). Individuals preferred physical and online treatment (Casey et al., 2014). Some research reports show that guided internet-based approaches can be as practical as face-to-face approaches (Lappalainen et al., 2014; Ballegooijen et al., 2014; Murphy et al., 2009).

Given the reason for the COVID-19 pandemic or travel issues, some parents preferred an online method. In addition, there is a slight preference for individual sessions compared to group sessions. It is not surprising that parents preferred individual sessions due to the stigma related to mental health issues in Asia (Zhang et al., 2019). On the other hand, parents prefer group sessions, possibly due to their belief that they might be helpful to learn from others' experiences and get support from each other (Breuer & Barker, 2015). The findings also suggest that most Malaysian children with chronic pain are using medication and only a few of them seek psychotherapy which is consistent with the finding that the majority of Malaysians who experience chronic pain will probably turn to hospitals and clinics that offer pharmacological and interventional pain reduction therapies (Cardosa et al., 2011). With the current treatment, they feel relief after receiving treatment but not completely. Due to a lack of awareness, stigma and policy insurance related to psychotherapy provided in Malaysia, most parents only seek treatment from a medical doctor (Hassan et al., 2018). The findings possibly suggest that parents in Malaysia are less likely to seek psychotherapy treatment for their children who suffer from chronic pain. One possible reason people preferring to seek help from GPs is that it is less stigmatizing to go to a GP's office rather than a psychiatrist's or psychologist's office. In addition, patients are often more at ease with doctors who do not work in a psychiatric unit (Hirosawa et al., 2002). These findings suggested that the general public in Malaysia was under-informed about mental health services and unable to recognize the need for help from different fields when handling chronic pain issues. The current sample suggests that parents of children with chronic pain conditions are motivated and open to ACT-based intervention. Based on the findings, developing a suitable protocol for the Malaysian context is relevant and needed. This study examines parents' perception of children with chronic pain conditions towards current treatment. Next, the research provides impact in terms of understanding the concept of psychological flexibility, chronic pain, psychological well-being and functioning and the relevant intervention such as ACT to society. When people are aware of the concept of psychological flexibility and chronic pain, people will be more conscious of the current condition they are experiencing. This

study also provides information to society and individuals regarding suggested available treatments. Besides, the study provides parents of young people with pain with suggestions and additional information for those who handle children with chronic pain. Parents can figure out the factors that might influence the effectiveness of treatment.

CONCLUSION

Limitation and future direction

The study has several limitations. Firstly, the small sample size may limit the generalizability of the study. Next, it focused on parental perception, and future studies may also gather the perception of young people. Besides, all measures used were self-reported. Hence, response biases may have influenced the results. Future studies can broaden the sample size and certain factors like education level and socioeconomic status. In addition, researchers can also include the children's perception of the intervention.

Last but not least, future research can also have a qualitative response to the study. In conclusion, the current sample suggests that parents of children with chronic pain are open to ACT-based intervention targeting psychological flexibility. In view of the positive attitude and perception from parents, there is support that an ACT treatment protocol tailored to young Malaysian chronic pain patients and their parents should be developed and tested.

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Conflict Of Interest:

The authors declare no conflict of interest.

Author's Contribution

Lim Jia Hang: writing manuscript, data collection, data analysis, and interpretation and Lee Sook Huey: conceive the ideas of study, writing, reviewing and editing of the manuscript.

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