

A WEB-BASED ACCEPTANCE AND COMMITMENT THERAPY INTERVENTION ON WELLBEING OF PARENTS WHOSE CHILDREN HAVE CHRONIC CONDITIONS



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DISCLOSURES (SUPPORT)

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- Relevant financial relationships (Kirsikka Kaipainen, Päivi Lappalainen, Raimo Lappalainen):
 - Co-founders of Headsted Ltd, the Finnish company which implemented the web intervention program

BACKGROUND

NEED FOR PSYCHOLOGICAL SUPPORT

- Parents of children with a chronic disease or functional disability have an increased risk of stress-related problems and reduced quality of life
- There is a lack of psychological support for this group
- They could benefit from treatments providing them with tools to handle difficult inner experiences that are evoked when facing challenges and hardships related to parenting a child with a chronic condition



WHY WEB-BASED TREATMENT?

- Web-based treatments offer a solution for delivering evidence-based psychological treatments for parents, who may often have challenges in finding time to access face to face services.
 - Many drop-outs in face-to-face treatments
- Advantages of web-based treatments
 - Not bound by time and place
 - Available when most needed
 - Flexible integration of the intervention into everyday life

PREVIOUS EVIDENCE: ACT FOR PARENTS

- Parenting and parental stress have been identified as an important focus of ACT (Blackledge et al, 2006; Coyne, et al, 2011)
- For instance, an ACT-integrated parenting intervention for families of children with cerebral palsy showed increased child functioning and quality of life, as well as decreased parental psychological symptoms (Whittingham, et al, 2015).
- **Psychological flexibility** has been linked to psychological symptoms, parental burden, and stress for different parental populations (Evans et al, 2012; Lloyd et al, 2008; Weiss et al, 2012; Whittingham et al, 2013).
- No previous results of ACT-based web interventions for parents.

A WEB-BASED ACCEPTANCE AND COMMITMENT THERAPY INTERVENTION FOR PARENTS

Randomized control trial

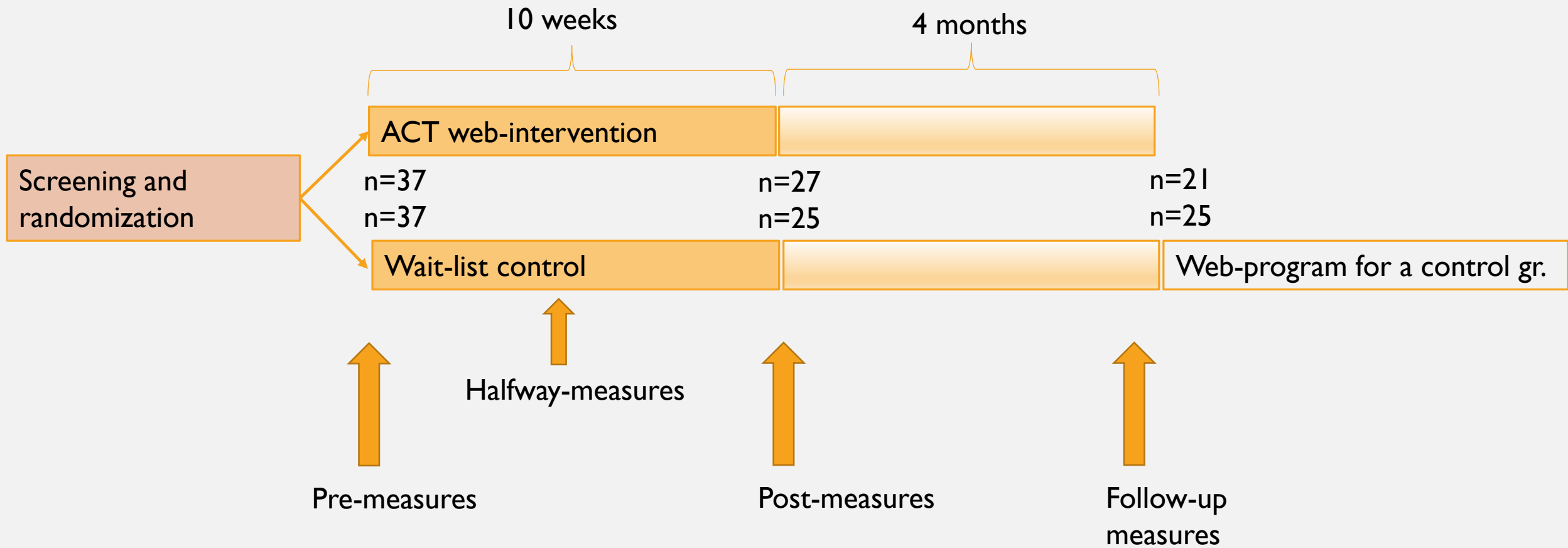
WE INVESTIGATED

1. The effect of a web-based ACT intervention vs. control (waitlist) on burnout and other psychological symptoms with parents of children having chronic conditions.
2. The effect of the intervention on ACT related processes including experiential avoidance (EA), mindfulness skills, and cognitive defusion.
3. Do changes in psychological processes mediate intervention effect on psychological symptoms?
4. Is engagement in the intervention linked to changes in burnout symptoms and mindfulness skills?

PARTICIPANTS

- Participants (N=74) were parents of children with type I diabetes or functional disabilities recruited through the pediatric clinic and the pediatric habilitation center of County Council.
- The parents had to have a score exceeding 2.75 points on the Shirom-Melamed Burnout Questionnaire (SMBQ) indicating significant burnout symptoms.
- The mean age of the participants was 42.6 ± 6.9 years (range 28–58).
- 60 mothers, 14 fathers (8 couples)
- 52% of the participants had a university level education.
- 48% of the children (N = 67) had type I diabetes and the others had long-term, inherent, or early psychological or physiological functional disabilities, including mostly ADHD, autism, Asperger syndrome, and cerebral palsy.

DESIGN



MEASURES

- Psychological symptoms
 - Burnout symptoms, SMBQ
 - Symptoms of depression, anxiety and stress, DASS
- Psychological processes
 - Experiential avoidance/ psychological flexibility, AAQ-II
 - Mindfulness skills, FFMQ: Observe, Describe, Acting with awareness, Non-react, Non-judge
 - Cognitive fusion, CFQ
- Engagement
 - Usage days, usage time and completion percentage of the web intervention
 - Satisfaction with the web intervention

ACT WEB-INTERVENTION

- 10 weeks
- Goal: to teach parents skills and strategies to prevent and handle stress and exhaustion in everyday life
- Personal coaches (17 psychology students):
 - Semi-structured **phone interview** before starting the web-program: lifestyles, social relationships, factors affecting wellbeing
 - Semi-structured **feedback five times** during the program about home assignments
 - No face-to-face contact
- Five modules
 - Email reminders sent after each module to parents who had not completed the reflection assignment

ACT WEB-INTERVENTION: 5 MODULES

Themes of the modules:

1. Life values
2. Value-based actions
3. Present moment
4. Defusion
5. Acceptance and self-compassion

Information texts and
videos
Exercises;
text and audio

Home
assignment/
reflection

Feedback
from the
coach

2 weeks

ACT FÖRÄLDRAR Coach Programmet Övningarna Diskussion Dagbok ACT

VÄLKOMMEN

Detta program

ETAPP 1: VAD ÄR VIKTIGT FÖR DIG?

ETAPP 2: MENINGSFULLA HANDLINGAR

ETAPP 3: NÄRVARO

ETAPP 4: DISTANS TILL TANKAR OCH KÄNSLOR

ETAPP 5: ÖPPENHET

SLUTORD

ACT föräldrar > Etapp 1: Vad är viktigt för dig? > Kurs i livet

- Viktigt för dig Meningsfullhet 90-års kalas Livsvärden Din kurs i livet

VIKTIGT FÖR DIG

Vad är viktigt för dig?



ACT FÖRÄLDRAR Coach Programmet Övningarna Diskussion Dagbok ACT

ACT föräldrar > Etapp 1: Vad är viktigt för dig? > Sammanfattning

Sammanfattning

SAMMANFATTNING

Under de senaste 2 veckorna har du fått läsa och reflektera kring dina livsvärden och det som gör livet meningsfullt för dig. Du har fått lysna på följande övningar:

- Viketkast i livet
- Video: Viktigt för dig
- Kärstan av meningsfullhet
- 90-års kalas

Du får fortsätta med dessa reflektioner. Hitta en plats där du kan sitta en stund ostört och lysna på dig själv. Vi har alla varit små en gång i tiden. Vi kan reflektera nutiden och det som är viktigt för oss utifrån denna perspektiv. Gå tillbaka till tiden när du var liten: *Lysna på rissten som kommer från lilla flickan eller pojken som finns inom dig. Hon eller han som sitter och drömlar med benen, och har drömmar och förhoppningar om vad livet kan föra med sig. Vad säger hon eller han? Vilka förhoppningar eller drömmar hade denna lilla flicka eller pojke?*

ETAPPENS ÖVNING

Reflektera kring dina livsvärden och formulera dem. Dela in livet i olika livsområden så är det tydligare att se vad som är viktigt. Välj ett eller flera livsområden och livsvärdering som du tycker känns angelägen för dig just nu.

Skriv ner dina tankar här:

- Familj och föräldraskap: Vad finns det för relationer som betyder mycket för dig? Hur vill du vara i dessa relationer, som mamma/pappa/partner/syster/bröder/dotter/son?
- Vänner: Är du den vän du vill vara? Hur skulle du vilja ha det?
- Fritidsintressen: Vad finner du en glädje i att göra? Vad skulle vara riktigt kul? Har du tidigare gjort något som du skulle vilja börja med igen?
- Jobb: vad skulle du vilja jobba med? Vad ger dig en känsla av mening när det gäller jobb?
- Hälsa och välmående: Vad betyder god hälsa och välmående för dig? Vad gör du för att ta hand om din hälsa och välmående, tex sömn och återhämtning?



ACT föräldrar > Etapp 1: Vad är viktigt för dig? > Kurs i livet

- Viktigt för dig Meningsfullhet 90-års kalas Livsvärden Din kurs i livet

DIN KURS I LIVET

Vi är alla på väg åt något håll, vare sig man är medveten om det eller inte. Var befinner du dig i livet just nu? I andra änden har vi det livet du skulle vilja leva. Du skulle... I andra änden har vi livet som kan bli om man förskjuter konsekvenserna och hålla sin oro, ilska, vrede och sina andra smärtsamma känslor i schack. Det gör du kanske genom att hålla dig undan från vänner och bekanta och sociala aktiviteter eller något annat.

Vilka är dina nuvarande strategier? Hur har de fungerat?

Kan du rita en pil nedanför för att visa var du befinner dig just nu och åt vilket håll du är på väg. Befinner du dig på den aktiva och meningsfulla sidan eller på den andra sidan? Skriv ner dina tankar.

Det går att "vandra" i en vredead riktning och samtidigt ha ett känslomässigt begäve med sig på resan.



Mer kontroll: Vad är det du vill kontrollera, undvika eller bli av med? Är det något som du har svårt att ta emot eller att vara öppen för? Vad gör du för att göra det?

Mer mening: Hur skulle ditt liv se ut när det är meningsfullt? Ett meningsfullt liv - vad innebär det för dig?

Spara

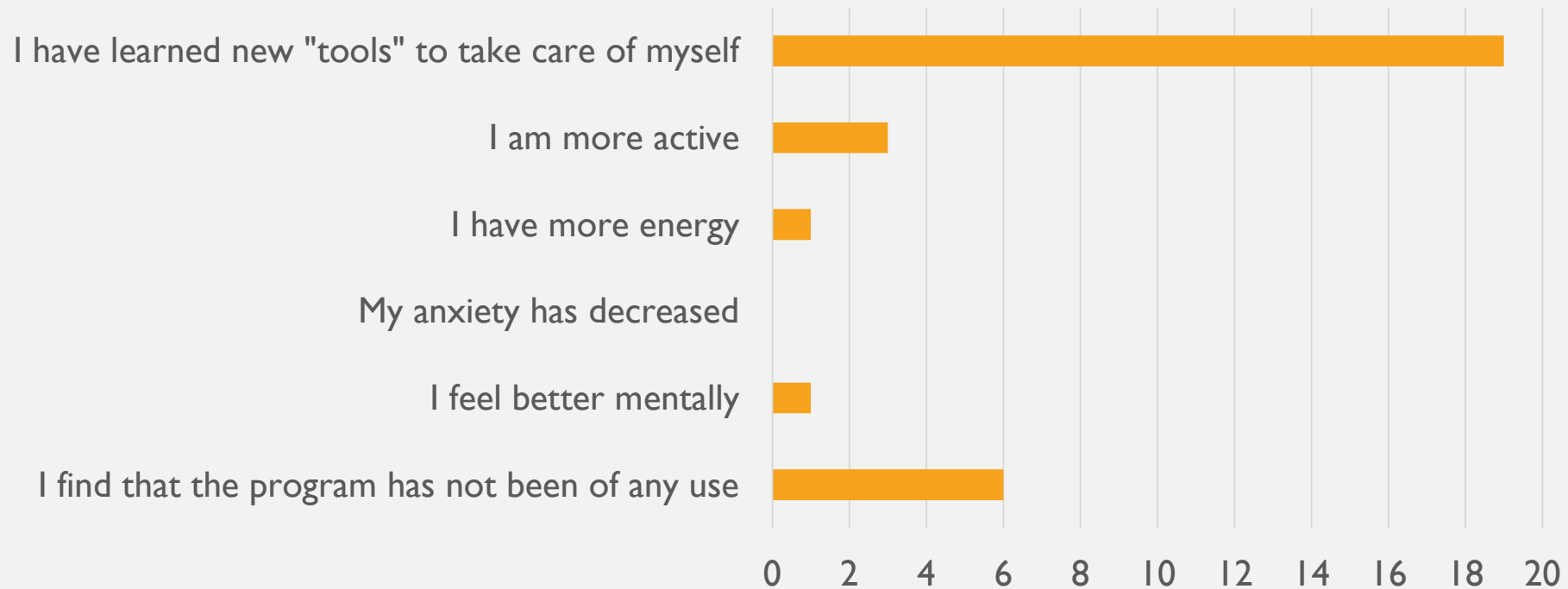
**RESULTS: OVERALL ENGAGEMENT
IN THE INTERVENTION**

USAGE ACTIVITY AND ENGAGEMENT (N=27)

Engagement metric	Description	Statistics
Usage days	Total number of days on which a participant accessed the web intervention	Median 12 days (mean 13.3; SD 8.9; range 2-36)
Total usage time	The sum of a participant's usage sessions in hours	Median 2.9 hours (mean 3.6; SD 2.2; range 1.1-8.5)
Completion percentage	Percentage of intervention content completed by a participant	Median 93.1% (mean 85.0; SD 18.7; range 32.8-100.0)
User satisfaction	Satisfaction with the web programme on scale of 1-10 (very dissatisfied – very satisfied)	Median 9.0 (mean 7.5; range 2-10)

PERCEIVED BENEFITS (N=27)

How did the research project benefit you?



“Reminder that you can't control everything that happens”

”Good to stop and reflect”

FEEDBACK ABOUT THE ACT-PROGRAM

- If your friend would need similar support, would you recommend the program for her/him?
 - Absolutely 43%, Probably 39%, I don't think so 18%, Absolutely no 0%

Benefits: "I've had new insights. I think a little differently and have more understanding towards things that happen to me and around me. Perceive some things in a totally new way. Take care of myself more."

Developing suggestions: "To get this program in an earlier stage after the child's diagnosis. About 6 months later when the shock has calmed down you can digest more information. That the clinic would then follow up and provide information that this kind of help is available."

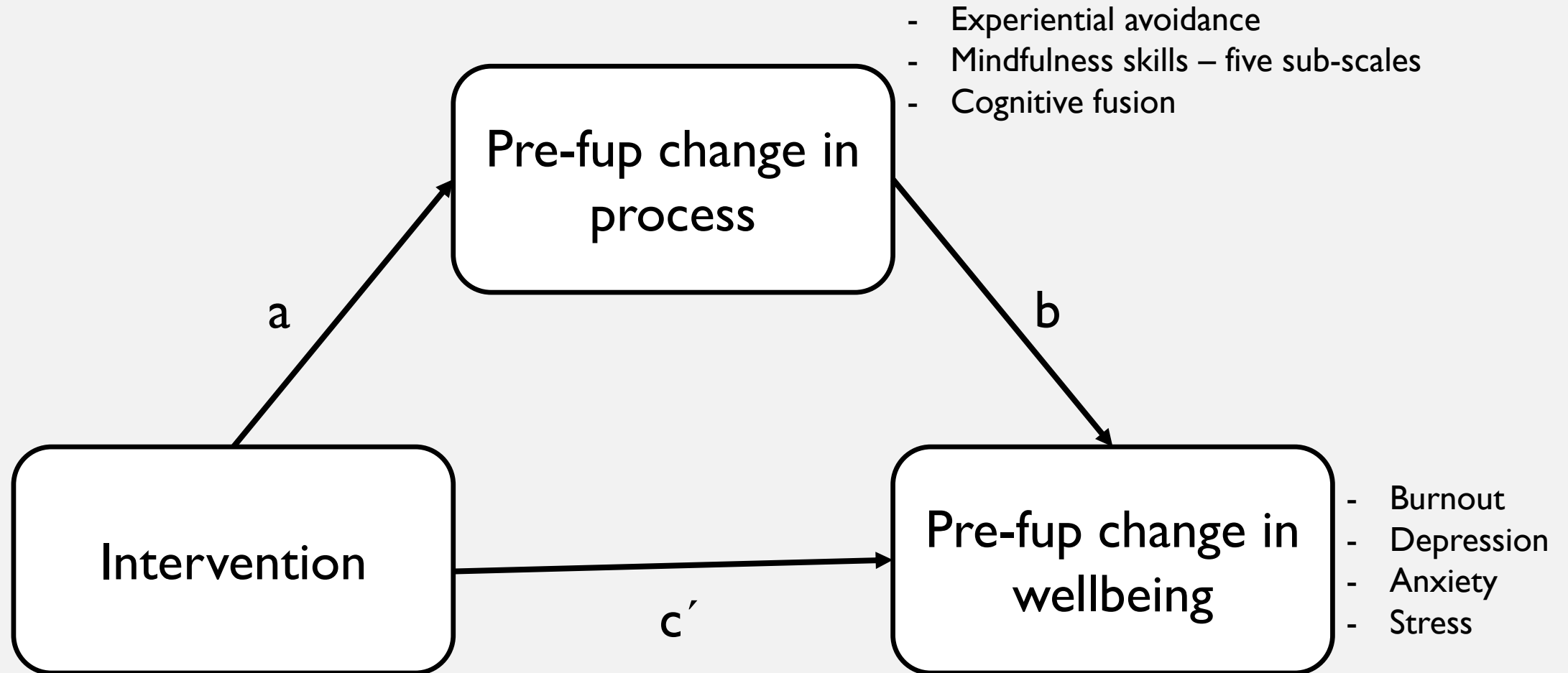
"Thanks for a great program! It was suitable in my life right now when I'm home and have been on a sick leave due to burnout for 3 months. The program has helped me. I have listened to exercises, been able to relax. I feel I've received some tools and I feel more equipped to recover!"

RESULTS: EFFECTS ON PARENTS WELLBEING

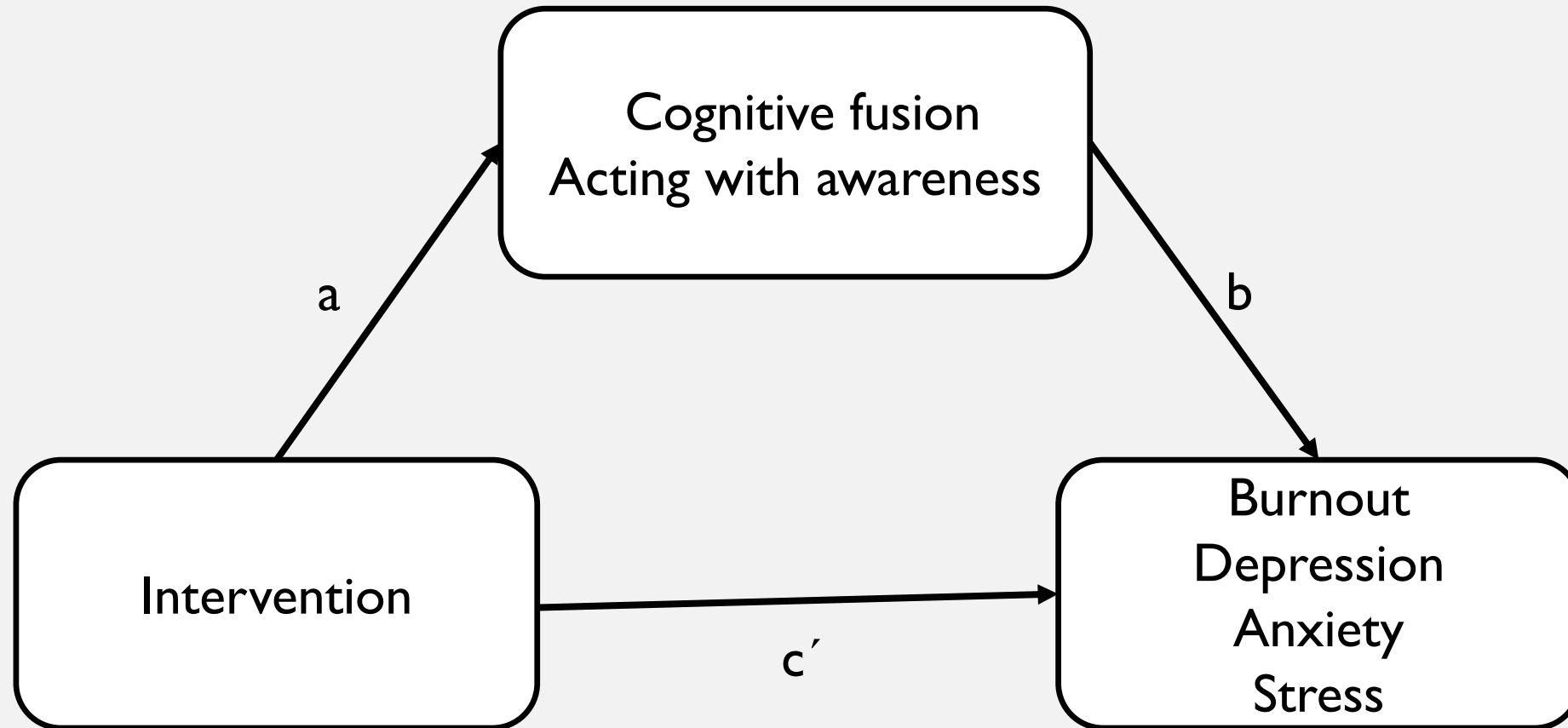
EFFECTIVENESS OF INTERVENTION ON PARENTS WELLBEING

- Significant improvements in ACT vs control group, Pre-Fup (HLM;Wald test, p-value <0.05):
 - burnout and depressive symptoms.
 - mindfulness skills of observing, describing, acting with awareness and non-reactivity as well as in cognitive defusion.
- All improvements were maintained at the follow-up measures four months after the guided intervention ended.
- Between-group ES:
 - Large ($d \geq .80$): burnout (1.62), depression (0.99) and anxiety symptoms (0.83) AND mindfulness skill of acting with awareness (0.91)
 - Medium ($d \geq .50$): stress AND cognitive fusion, observing, non-judgement and non-reactivity
 - Small ($d \geq .20$): psychological flexibility and describing.

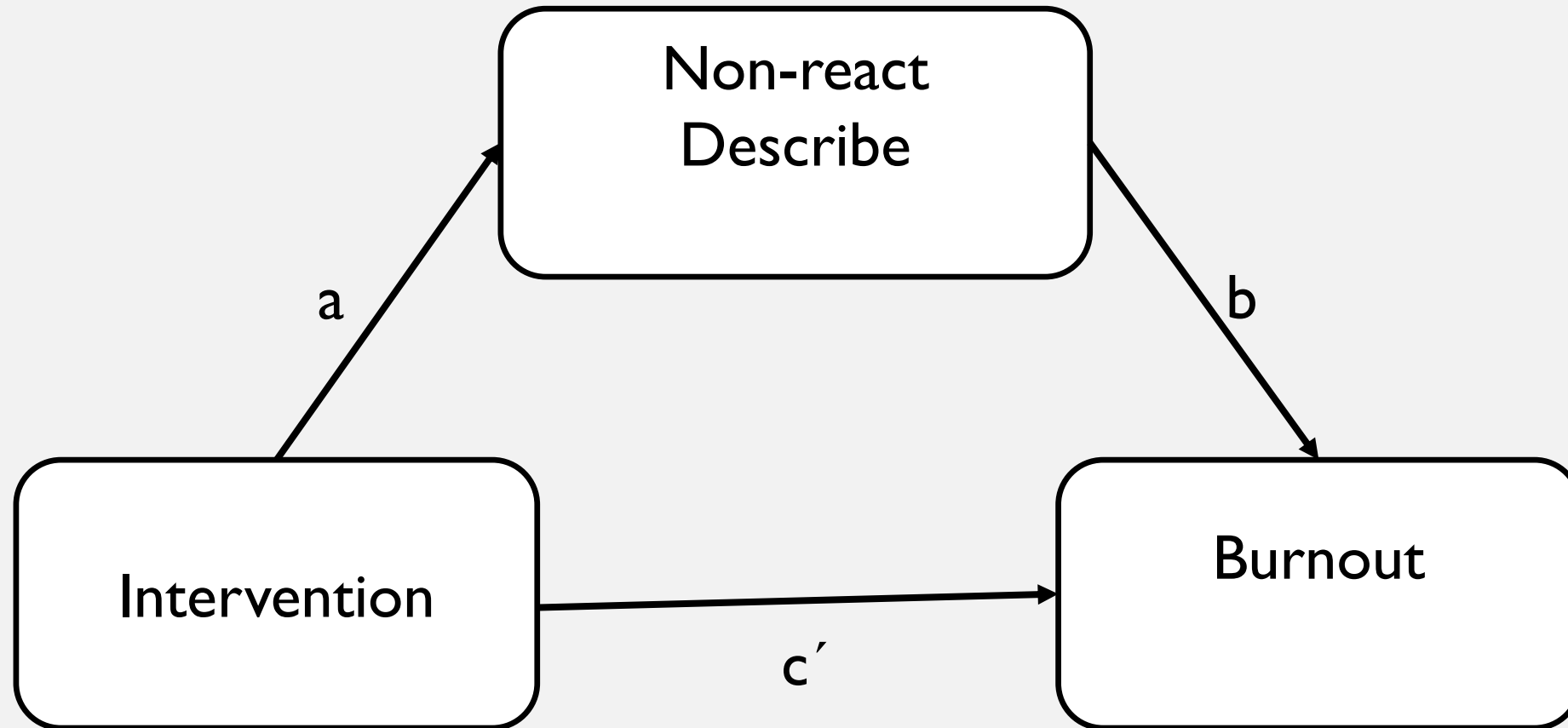
DO CHANGES IN PROCESSES MEDIATE THE EFFECTS ON WELLBEING?



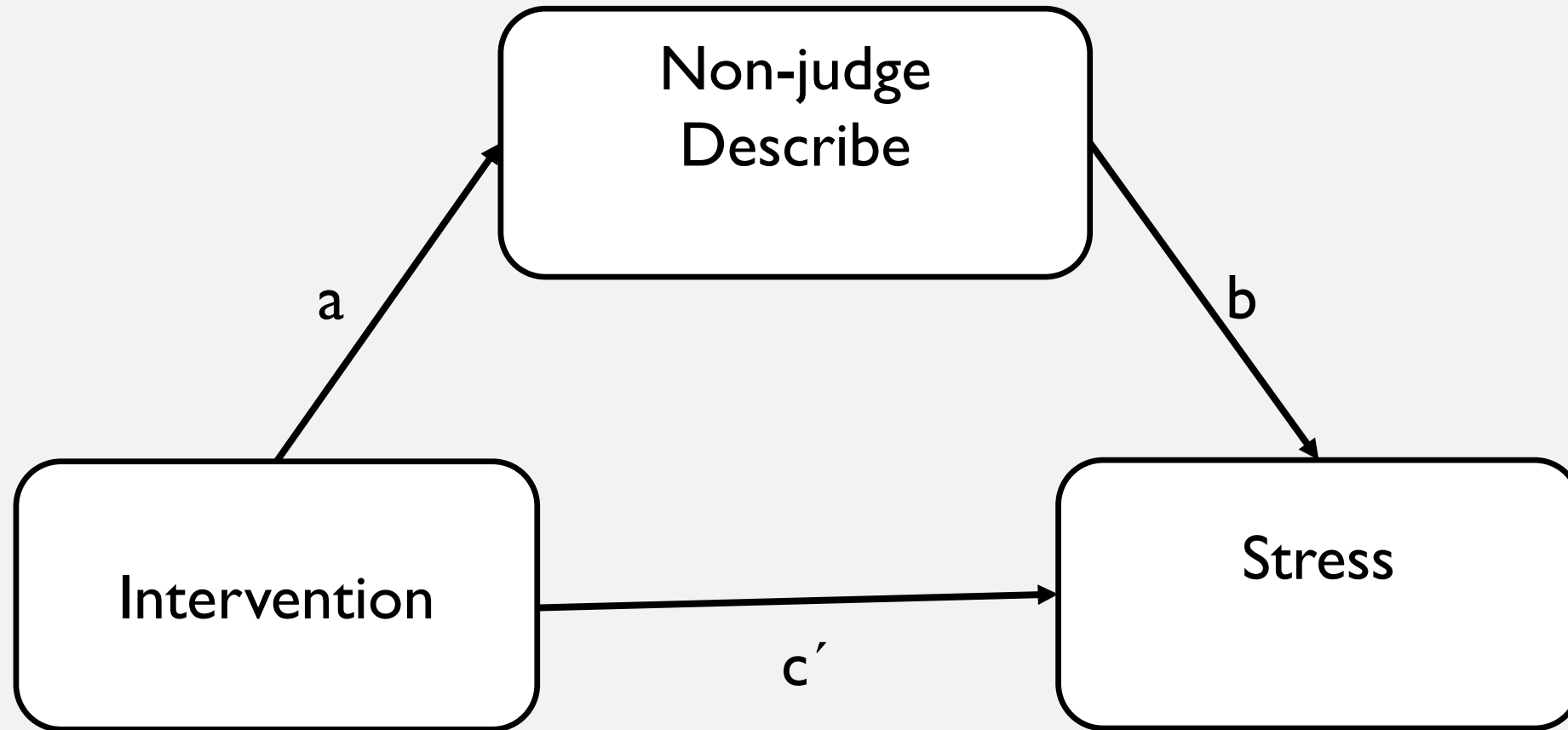
MEDIATORS: RESULTS I



MEDIATORS: RESULTS 2



MEDIATORS: RESULTS 3



**DOSE-RESPONSE: IS ENGAGEMENT
LINKED TO CHANGES?**

INITIAL ANALYSIS

- Associations between engagement metrics and pre-post changes in outcome and process measures were examined with partial correlations, controlling for respective baseline scores
 - Outcome measure: SMBQ (burnout symptoms)
 - Process measures: FFMQ (mindfulness skills, with subscales) and CFQ (cognitive defusion)

INITIAL RESULTS: PRE-POST CHANGES X ENGAGEMENT

	Usage days	Usage time	Completion percentage	Satisfaction
SMBQ	.07 (.75)	.24 (.25)	.19 (.37)	.18 (.40)
FFMQ	.25 (.23)	.25 (.23)	.39 (.05)*	.44 (.03)*
FFMQ Observe	.28 (.17)	.33 (.10)	.23 (.26)	.39 (.05)*
FFMQ Describe	.12 (.57)	.15 (.46)	.19 (.35)	.12 (.58)
FFMQ Awareness	.02 (.91)	.12 (.55)	.28 (.16)	-.29 (.16)
FFMQ Non-react	.20 (.33)	.36 (.07)	.23 (.25)	.51 (.008)**
FFMQ Non-judge	.11 (.60)	.11 (.59)	.47 (.02)*	.04 (.84)
CFQ	.23 (.26)	.19 (.36)	.43 (.03)*	.22 (.27)

CONCLUSIONS AND CLINICAL IMPLICATIONS

CONCLUSIONS

- A web-based ACT intervention can be used to improve psychological wellbeing of parents of children with chronic condition suffering from burnout symptoms.
- Our results provides evidence for the processes of change stated by an ACT-model
- Promoting cognitive defusion and mindfulness skills, especially acting with awareness, seems to be beneficial in order to affect parents' psychological symptoms
- Usage activity does not seem to be associated with changes in burnout symptoms, mindfulness skills or cognitive defusion skills
 - Participants were instructed to apply the exercises in the programme into their everyday life; we did not assess how actively they did so

FUTURE DIRECTIONS

- Engagement measures should be developed further, e.g.
 - Extent of reflection by writing
 - Ecological momentary assessment and weekly self-assessment
 - Increasing value-related activities
- Need of a personal coach should be investigated, i.e., Is a personal coach needed in a web-intervention or would it be used independently?
 - Quality and amount of feedback and support

THANK YOU!