Peer-to-peer support: Digital social networking to improve quality of life in people with aphasia*

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Disclosure

There are no conflicts of interest to declare.

Research Context

- Intervention study: Peer-to-peer support: digital networking in aphasia to improve quality of life (PeerPAL)
- 2020 – 2023

Research questions:

- How effective is networking with an aphasia-friendly digital social network tool in improving QoL?
- How effectively can reduced psychological well-being be prevented?
- To what extent is increased social participation achieved?

Background

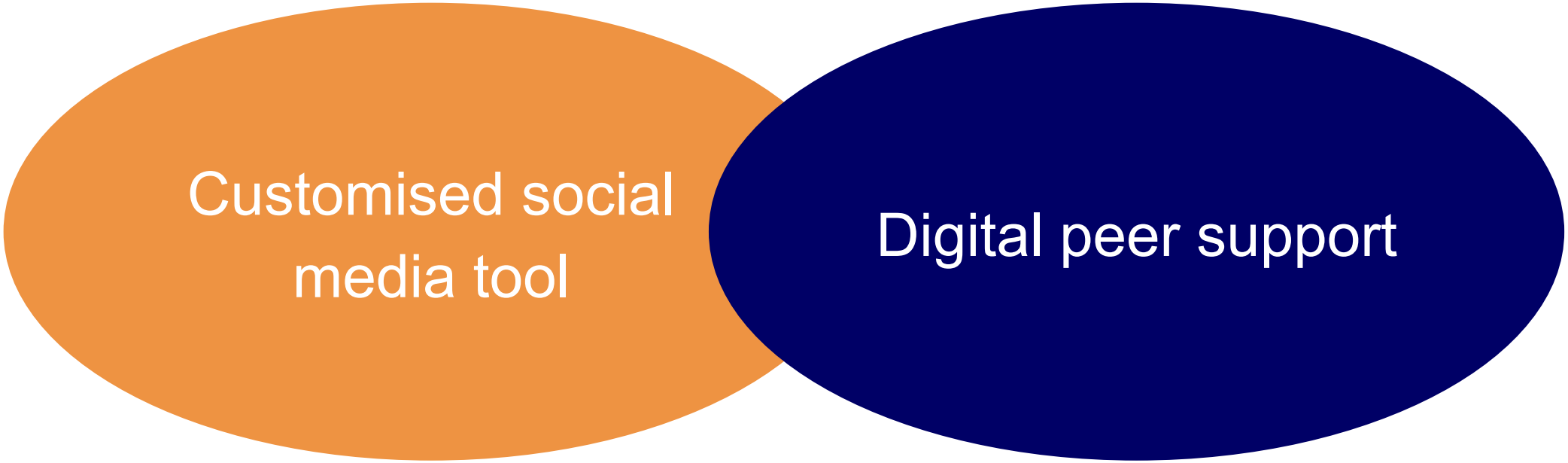
Quality of life & peer befriending

- people with aphasia (PWA) experience a decrease in quality of life with losing social contact (Fotiadou et al., 2014; Ellis et al., 2019)
- peer-befriending can lower levels of distress (Hilari et al., 2021) → However: is mostly professionally guided
- Social networking tools facilitate autonomous inter-action among PWA, when linguistically and visually simplified (Buhr et al., 2017)

However:

- there is no mediation of 'matching' PWA with regard to similar interests
- no face-to-face meetings

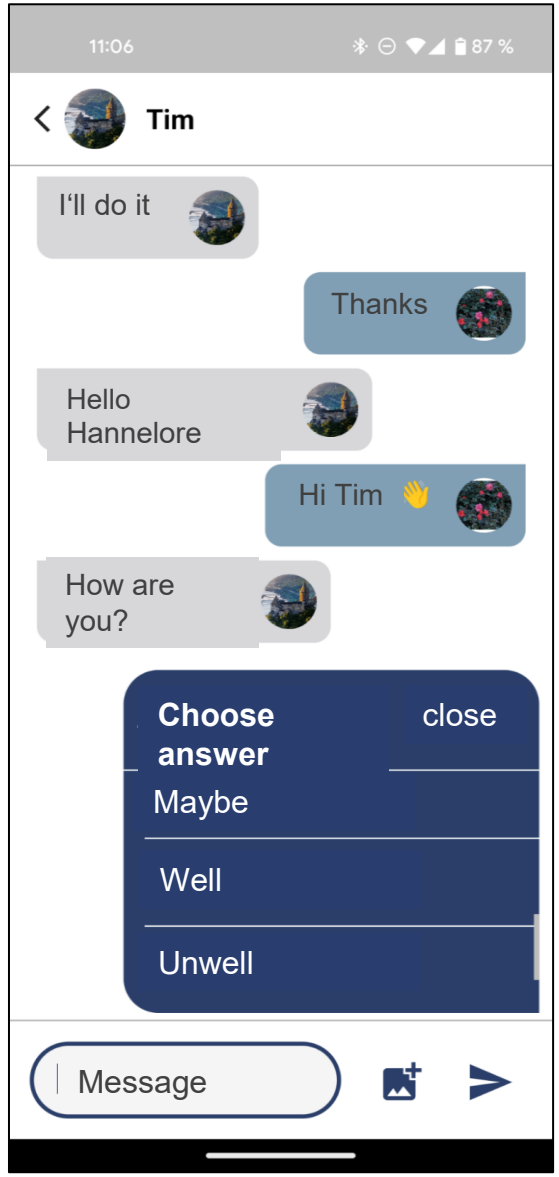
Aims



Study design & Method

PeerPAL App

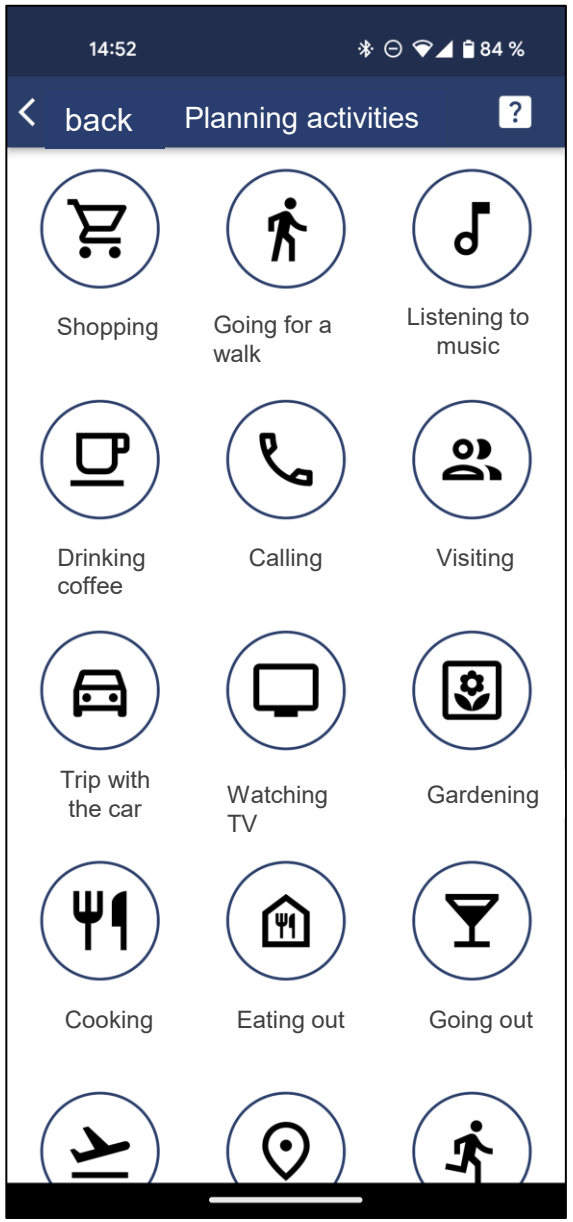
- Aphasia-friendly interface design
  - simplified instructions, commonly used words
  - simplified menu hierarchy: clear design
  - minimized use of swipe gestures
- Further support tools
  - text components, especially for initiating conversations
  - reminder function for activities
  - explanatory videos

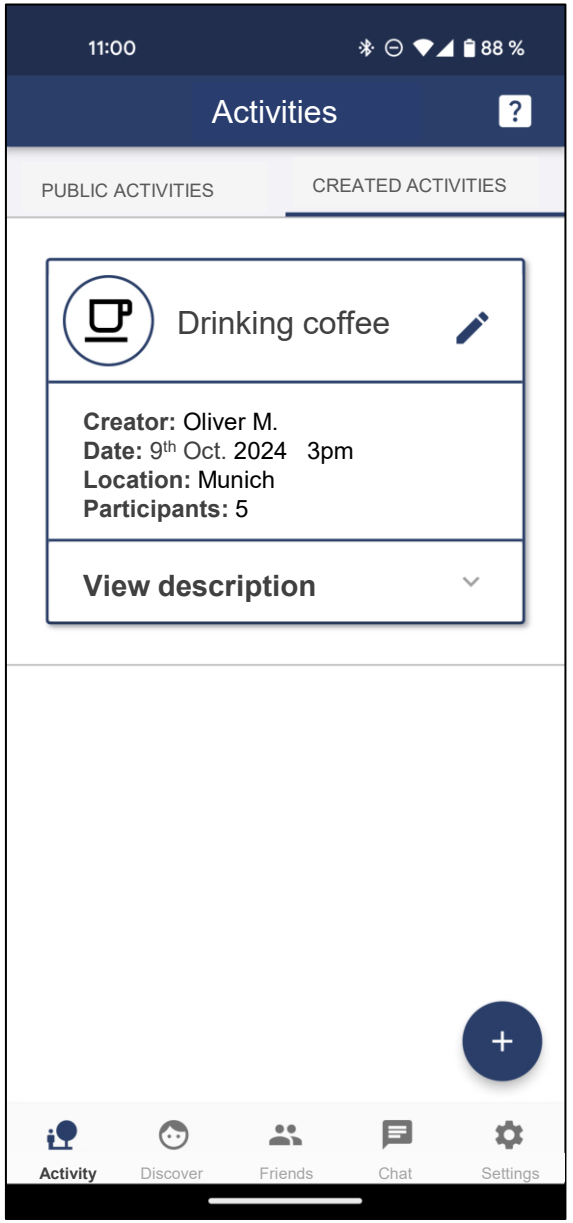


Chat

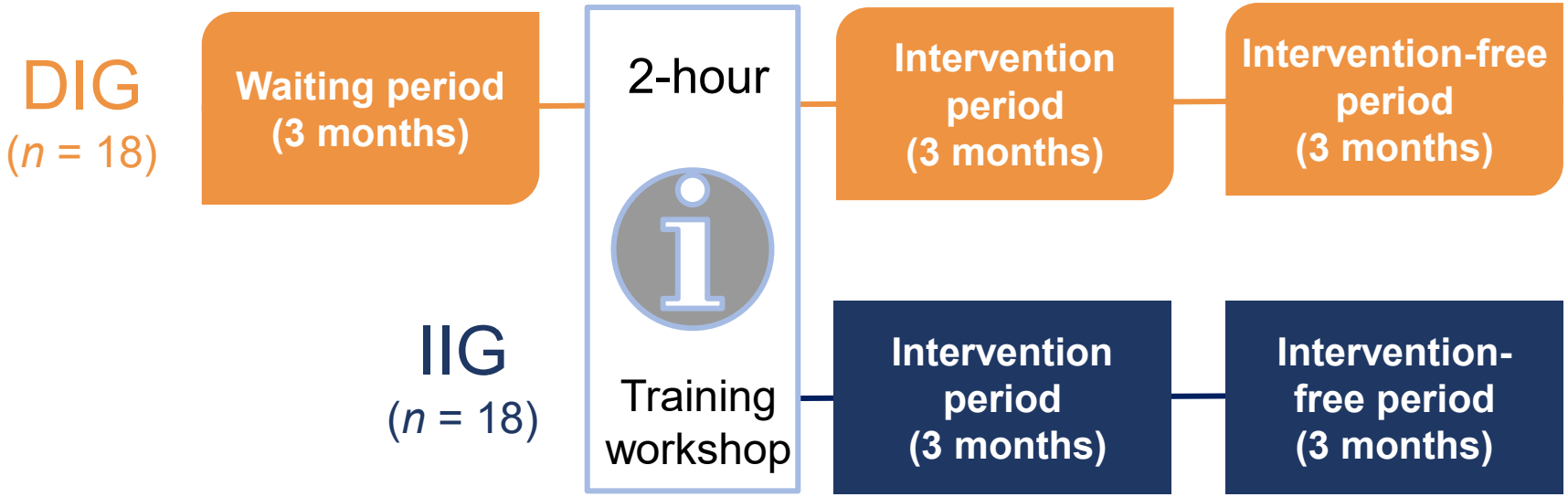
PeerPAL App

- Plan activities
  - select activity
  - set location and time
  - invite other users





Study design



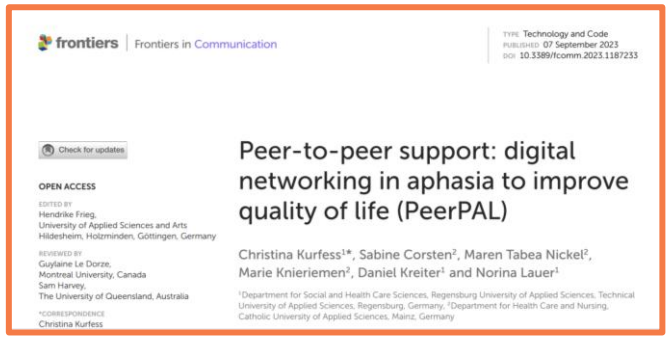
t0a — baseline

t0(b)

t1 — Posttest (incl. interviews)

t2 — follow-up

DIG = Delayed intervention group; IIG = Immediate intervention group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Peer-to-peer support: digital networking in aphasia to improve quality of life (PeerPAL)

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Outcome measurements

	Outcome	Measurement
Primary	**Health-related quality of life (HRQL)**	**SAQOL-39g (Stroke and Aphasia Quality of Life Scale-39; Hilari et al., 2009)**
Secondary	HRQL	GHQ-12 (General Health Questionnaire, Goldberg & Williams, 1988)
	Depression	GDS (Geriatric Depression Scale, Sheikh & Yesavage, 1986)
	Depression	DISCs (Depression Intensity Scale Circles; Turner-Stokes et al., 2005)
	Perceived social support and relationships	F-SozU (Social Support Questionnaire; Fydrich et al., 2007)
	Communicative participation	CPIB (Communicative Participation Item Bank; Baylor et al., 2013)

Results

Participants

	All participants (*n* = 36)	Delayed intervention group (DIG) (*n* = 18)	Immediate intervention group (IIG) (*n* = 18)	*p* value
Age at inclusion (years)	56 (49-59)	55 (42.5-59.5)	57.5 (52-59.25)	0.419
Biological sex				0.285
Female	11 (30.6%)	4 (22.2%)	7 (38.9%)	
Male	25 (69.4%)	14 (77.8%)	11 (61.1%)	
Time post-onset (months)	78 (39-177)	90 (48-183)	70 (28.75-171)	0.457
Aphasia severity[a]				0.793
Mild	19 (52.8%)	10 (55.6%)	9 (50%)	
Moderate	11 (30.6%)	5 (27.8%)	6 (33.3%)	
Severe	6 (16.7%)	3 (16.7%)	3 (16.7%)	

Values shown as median (interquartile range) or numbers (percentage). Due to rounding percentages not sum up to 100%. Group differences are calculated using the Mann-Whitney *U* test and expressed as *p* values.

[a] Determined with the Screening of the Aachen Aphasia Test (AAT; Huber et al., 1983)

Results – Primary outcome (*n* = 36)

SAQOL-39g (possible values)	t0(b) Median (IQR)	t1 Median (IQR)	Intervention period* *z* value	*p* value	Effect size (95% CI)	t2 Median (IQR)	Follow-up period* *z* value	*p* value	Effect size (95% CI)
Total (1-5)	3.90 (3.38-4.26)	3.99 (141.50-171.50)	-3.043	0.002	-0.598 (-0.796—0.296)	4.05 (3.56-4.29)	0.049	0.967	0.010 (-0.354-0.371)
Physical (1-5)	4.41 (3.69-4.60)	4.27 (3.94-4.82)	-2.590	0.010	-0.529 (-0.753—0.184)	4.50 (4.02-4.77)	-0.259	0.802	-0.052 (-0.416-0.327)
Communication (1-5)	3.00 (2.57-3.61)	3.43 (2.71-4.00)	-1.761	0.079	-0.598 (-0.626-0.024)	3.21 (2.82-4.00)	0.570	0.575	0.116 (-0.274-0.472)
Psychosocial (1-5)	3.90 (3.27-4.15)	4.03 (3.68-4.32)	-2.376	0.018	-0.474 (-0.719—0.124)	3.97 (3.38-4.40)	0.098	0.930	0.020 (-0.365-0.400)

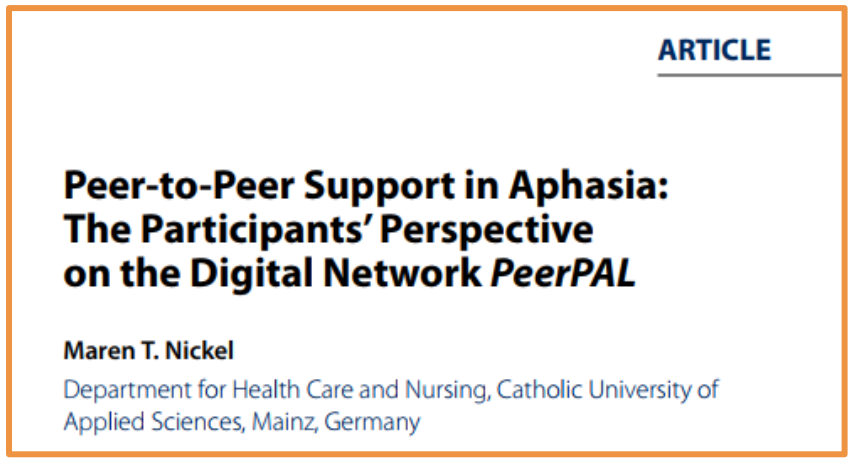
* Comparison with two-tailed Wilcoxon signed-rank test
IQR = Interquartile range, CI=Confidence interval

Results

- ✓ no change in measurements of depression
- Qualitative Findings:

P: But, so, activities is, I like it. So, that was really great.

I: That means, you have also written with other people from other regions?
P: Yes, so (…) has also searched and found contact …, so yes, that was very good.



Conclusion & Outlook

Conclusion

- PWA can use the app
- therapy-specific improvements in HRQL (SAQOL-39)
- no negative change in psychological well-being

→ online peer befriending is effective

Outlook

Sustainability of digital solutions

Establishing the app in the care of PWA

- Accessibility: Open source code
- Usability: Influencing factors (Nickel et al., 2025)

Support of using mainstream social media tools

- Literacy: Workshops etc.

Literature

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PeerPAL

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Thank you for your attention!!

https://github.com/logo-othr/peerpal

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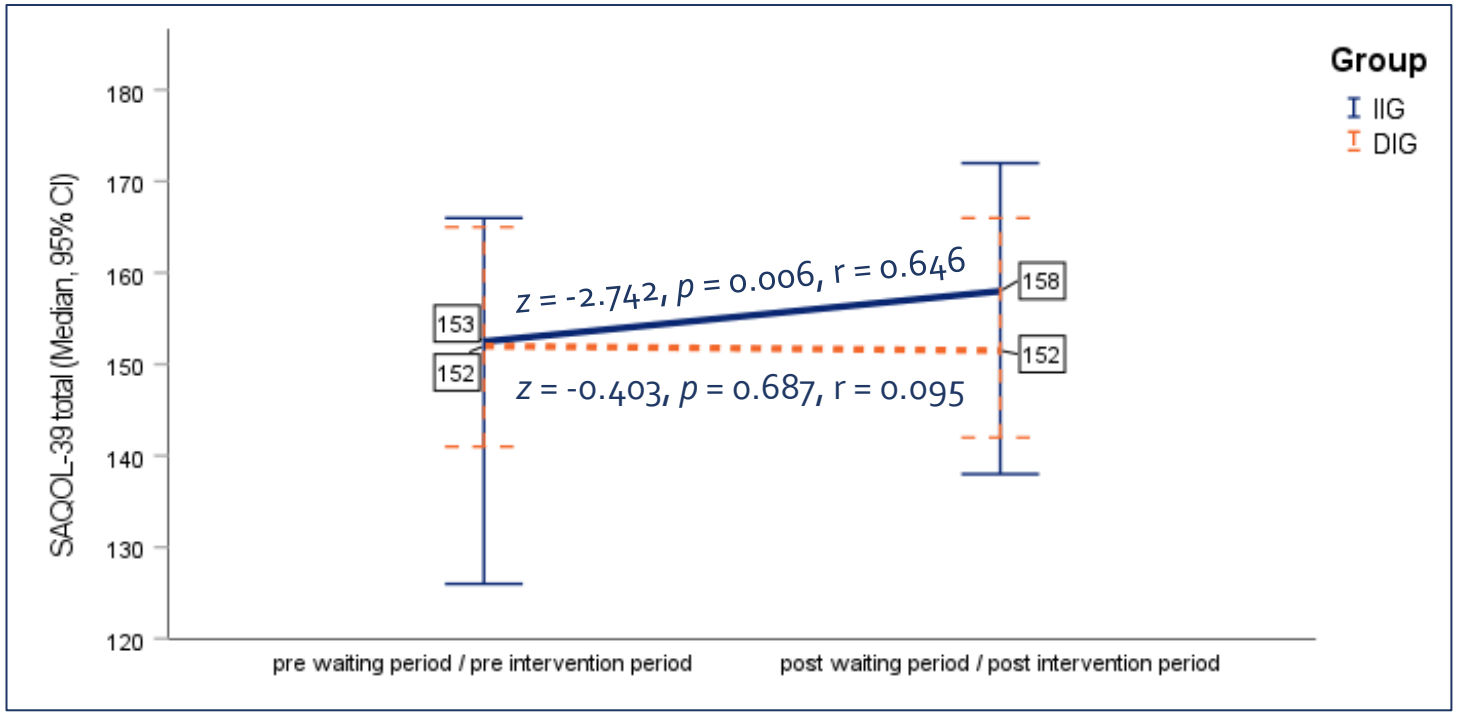
Appendix

Comparing intervention and waiting period

- Delayed intervention group (DIG) during the waiting period
  (*n* = 18) with the Immediate intervention group (IIG) during the intervention period (*n* = 18)
- ➢ significant deviation in the differential scores of the SAQOL-39 total
  (*U* = 94.5, *z* = -2.138, *p* = 0.033)



* Comparison with two-tailed Wilcoxon signed-rank test in each group

Results – Secondary outcomes (*n* = 36)

Outcome measures (possible values)	**t0(b)**	**t1**	**Intervention period**			**t2**	**Follow-up period**		
	Median (IQR)	Median (IQR)	*z* value	*p* value	Effect size r	Median (IQR)	*z* value	*p* value	Effect size r
GHQ-12 (0 – 36)	25 (21.25-28.75)	27 (24.25-29.75)	-1.955	0.051	0.326	27 (24.00-30.00)	-0.331	0.741	0.055
CPIB (0 – 30)	15 (12.00-17.00)	15 (11.50-19.00)	-1.040	0.298	0.173	15.5 (11.25-17.00)	-0.638	0.523	0.106
F-SozU (14 – 70)	59.5 (50.25-65.00)	59.5 (53.25-65.25)	-1.113	0.266	0.186	59.5 (53.75-66.00)	-0.944	0.345	0.157
DISCs (1 – 6)	5 (4.25-6.00)	5 (4.00-6.00)	-0.626	0.532	0.104	6.00 (5.00-6.00)	-1.380	0.167	0.230
GDS (0 – 15)	13 (11.00-14.00)	13 (12.00-13.75)	-0.743	0.458	0.124	13 (11.00-14.00)	-0.282	0.778	0.047

* Comparison with two-tailed Wilcoxon signed-rank test
IQR = Interquartile range