Health literacy among caregivers of children with IgE-mediated allergy at risk of anaphylaxis

Josefien Vandekerckhove [a], Barbara De Wilde [b], Karolien Van de Maele [c], Yvan Vandenplas [a], Dominique Bullens [d], Jasmine Leus [b,d]

[a] Vrije Universiteit Brussel, UZ Brussel, KidZ Health Castle, Brussels, Belgium
[b] Pediatric department, AZ Maria Middelares Gent, Ghent, Belgium
[c] University of Antwerp, Antwerp University Hospital, department of pediatrics, Edegem, Belgium
[d] Laboratory of Pediatric Immunology, Department of Microbiology and Immunology, KU Leuven, and Clinical Department of Pediatrics, University Hospitals Leuven, Leuven, Belgium

josefien.vandekerckhove@gmail.com

Keywords

Food allergy, health literacy, patient education, training session, venom allergy

Introduction

Anaphylaxis is an acute, life-threatening multi-systemic allergic reaction (1). The prevalence in children is increasing, resulting in more hospital admissions over the last decade (2). Some anaphylactic reactions may be fatal if not treated appropriately, but the fatality rate is low (<0.001%) (3). The most common trigger in children is food. The prevalence of food allergy in European schoolchildren is estimated to be 4-7% (4). The epidemiological data of anaphylaxis are probably underestimated due to under-diagnosis and underreporting (3). A European study identified peanuts as the most frequent trigger, followed by wheat, hen's egg and cow's milk (5). Under the age of 3 years anaphylaxis is mostly triggered by hen's egg and cow's milk. Most children acquire tolerance for the latter products with age. Therefore, the prevalence of anaphylaxis due to food is higher in young children (2).

Complete avoidance of the food allergen remains crucial, but accidental exposure is common (6). Caregivers of children with anaphylaxis therefore need an action plan to manage severe reactions. The adrenaline auto-injector is the first line therapy for all anaphylactic reactions and should be available for all patients at risk (6). Parents report a lack of information at diagnosis that increases both anxiety and uncertainty in managing an accidental ingestion (7). Several guidelines recommend the provision of comprehensive information on allergen avoidance, reading food labels, rapid recognition of symptoms and management of allergic reactions, with education on how and when to use the adrenaline auto-injector (4,8-11).

According to a recent study based on data of the Allergy Vigilance Network the prevalence of food-allergic anaphylactic reactions at school in France is 28% (12). Most fatal cases of anaphylaxis at school are attributed to a delay in the initial treatment due to lack of recognizing symptoms and/or delay in using the adrenaline auto-injector (10). Adequate education of family members and training in non-clinical settings such as schools, is advised to improve this lack of knowledge (6).

Health literacy is defined as people's knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgments and decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during one's life course (13). The general level of health literacy is quite limited in Europe (13). A higher level of health literacy is necessary to optimize the management of anaphylaxis. To improve the caregivers' level of health literacy, their level of self-efficacy needs attention. Self-efficacy is defined as confidence and 'the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations' (7). Improving self-efficacy through education has been shown to be effective in improving quality of life, self-management and coping with asthma and other long term conditions (7). Several previous studies about self-efficacy in the management of anaphylaxis at school have shown that the self-efficacy score improved by education (10, 14-16).

The goal of this study is to assess the effect of a training session on caregiver's knowledge and self-efficacy in managing children with IgE-mediated allergy at risk of anaphylaxis. We assumed that a group training session about anaphylaxis would improve the level of health literacy by increasing the level of knowledge and self-efficacy of the caregivers.

Materials and Methods

Study design

We conducted a prospective cohort study in a population of caregivers of children with IgE-mediated food or insect venom allergy at risk of anaphylaxis at a regional hospital in Belgium (AZ Maria Middelares Ghent). The protocol was approved by the institutional Ethics Committee (committee's reference number: MMS.2020.017) and was registered in clinicaltrials.gov (NCT04475003). A written informed consent was obtained from all participants. The data were collected and analyzed by the researchers (J.V., J.L. and D.B.), and an independent academic statistician.

Study population and procedure

The subjects enrolled in this study were caregivers (parents, grandparents, crèche supervisors and teachers) of children with IgE-mediated food or insect venom allergy at risk of anaphylaxis. Eligible caregivers were recruited during outpatient consultation from 30 July 2020 till September 2021. During consultation parent(s) were extensively informed by the pediatrician specialized in allergy. They received an information leaflet, were taught how to use the adrenaline auto-injector and - in case of food allergy - also visited a dietician specialized in allergy. All Dutch speaking parents and related caregivers were then invited for a training session 3-4 months after diagnosis. We invited all caregivers to participate the study, so there was no bias in favor of some profiles. The session was always given by the same pediatrician specialized in allergy. A maximum of four caregivers per patient were allowed to participate. All caregivers were informed about the purpose of the research and the voluntary nature of participation. The two hours training consisted of a theoretical and practical part, and ended with a Q&A session. During the practical part each caregiver learnt how to use the adrenaline auto-injector with a trainer pen and how to read food labels. Before the start of the session the caregivers filled in a paper questionnaire. During the Covid pandemic the sessions were digital, so the questionnaire

was sent online a few days before the training. One week after the training all caregivers received the same survey online. If the questionnaire was not completed, reminders were sent several times. Four training sessions were organized, two live and two digital, and each participant followed one session. All training sessions (digital, live) were given by one and the same pediatrician specialized in allergy. Two sessions were cancelled due to the pandemic. The digital session was a live, online non-recordable session. There was no possibility to obtain the PowerPoint slideshow afterwards and the participants were not allowed to take screen shots of the power point slides.

Questionnaire

The questionnaire was specially designed for this study and consisted of three parts: twelve multiple choice and true-false questions about anaphylaxis, a Dutch translation of a validated questionnaire with eight multiple choice questions (answering scores from one to five, one meaning 'I cannot do that at all' and five meaning 'I certainly can do this') about self-efficacy of caregivers in the management of anaphylaxis (S.PER.SE-FAAQ) and a section with demographic information (caregiver type, level of education, age and sex) and one final question 'To what extent did this training session make you feel more confident in taking care of a child at risk of anaphylaxis?', scoring zero to ten, zero meaning 'no added value', ten meaning 'absolutely of value' (10).

Statistics

The data were analyzed with the SPSS IBM version 26 using nonparametric statistics (Wilcoxon Signed Ranks Test). Univariate Regression analysis with knowledge/self-efficacy as dependent factor, and age, type of caregiver, education level and type of training session as independent factors, was performed. The primary outcomes were the effect of the training session on the total score of caregivers' knowledge and self-efficacy. P-values below 0.05 were considered statistically significant. Bonferroni adjustment was used when necessary.

For the power calculation we used the first part of the questionnaire (knowledge). In order to have a power of 90% (SD of 35% for an - = 0.025) we had to include at least 62 participants. Prior to the study, J.L, J.V. and B.D. agreed that the effect of the training session would be clinically relevant if the difference in total knowledge score was an improvement of two out of twelve questions (16 %). The secondary outcome was the subjective score on the question whether the session contributed in feeling more confident in taking care of a severe allergic child.

Results

Population description (table 1)

One-hundred-forty caregivers followed the training sessions and could be eligible for this prospective cohort study, 116 people agreed to participate and completed the first questionnaire. Forty-five out of 116 (39%) participants did not complete the questionnaire after the training (partial responders). Seventy-one participants completed the questionnaire twice (complete responders), of which 69% were below 55 years, the majority (70.4%) of them were female. Most caregivers (40.8%) were first-degree relatives (parent, sister), followed by second-degree relatives (grandparents, aunt, uncle) (33.8%) and school- and nursery caregivers (25.4%). The majority of school caregivers were teachers (19.7%), followed by one director (1.4%), one school manager (1.4%), one speech therapist (1.4%) and one childcare supervisor (1.4%). Most participants (85.9%) were higher educated (master's or bachelor's degree). Thirty-five caregivers (49.3%) followed the live training session, 36 (50.7%) the digital session.

Knowledge (figure 1)

The median total knowledge score before the training for both complete and partial responders was 66.7%, afterwards 83.3%. This was a significant improvement (p< 0.001). The difference in total score of knowledge was an improvement of two out of twelve questions (16.6%) which means a clinically relevant improvement in the complete responders group.

Subgroup analyses (table 2)

The younger participants (<55 years old; n=49/71) had a higher median score before (75% versus 58.3%; p=0.03) and after the training session (83% versus 75%; p= 0.005) in comparison to the older participants (≥55 years; n=22/71). In both age groups, the total knowledge percentage significantly increased. The caregivers who followed the live training session (n=35/71) had a higher median knowledge score before the training (75% versus 66.7%, p=0.024) in comparison to the caregivers who followed the digital session (n=36/71). After the training session the median knowledge score was equal in both groups. The total knowledge score significantly increased in both groups after the training session. No difference in baseline knowledge score was observed between the type of caregiver or their level of education. All caregiver groups however improved their total score on the knowledge percentage significantly. After the training session the scores differed significantly across the caregiver groups (p=0.003); post-hoc we saw a significantly lower knowledge score in the second degree caregivers compared to the other caregiver groups (p<0.001). The effect of training was not different between levels of education, but we observed that all groups improved their level of knowledge.

Correlations

In a stepwise, univariate regression analysis for the difference in knowledge before and after the training session as dependent variable age category, type of caregiver, education level and type of training session (live/digital) are not withheld as significant influencing factors.

Self-efficacy (figure 2)

The median total score of self-efficacy before the training session for both complete and partial responders was 80%, afterwards 85%. This was a significant improvement (p<0.001).

Subgroup analyses (table 3)

No difference in baseline median total self-efficacy score depending on age, caregiver type, degree of education and type of training session could be observed. All groups improved their score on self-efficacy significantly, no difference was seen after training amongst the different groups.

Additional information

Forty-six participants answered the additional question "To what extent did this training make you feel more confident in taking care of a child at risk of anaphylaxis? Only one participant felt that the training session had no added value at all. The others were more confident after the session, with scores of seven and higher out of ten.

When asked how they preferred to receive information, a significant number of caregivers (39.4%) chose the training session, followed by written information in a paper leaflet (23.9%), written information on a website (22.5%), an online group with peers (8.5%) and an information video on a website (5.6%).

Discussion and Conclusion

4.1 Discussion

This is the first Belgian study reporting the effect of an additional group training about anaphylaxis on knowledge and self-efficacy of caregivers of children at risk of anaphylaxis. Parents often are unable to inform other caregivers about the diagnosis of anaphylaxis. Therefore we decided not only to invite the parents, but also second-degree relatives and school caregivers. The training session consisted of a theoretical, a practical part and a discussion moment. We concluded that the training session resulted in a significant improvement of the knowledge score in the complete responders group (66.7% to 83.3%). This improvement was clinically relevant as we had agreed that there should be an improvement of at least 16%. Furthermore, the training resulted in a significant improvement of the median total score of self-efficacy (80% to 85%). The self-efficacy questionnaire had to be answered on a scale of one to five, so we could not define how much improvement there had to be in order to be clinically relevant. These results were consistent with previous studies on the effect of training session on self-efficacy (10, 14-16). The effect of a training

Table 1: population characteristics

Population characteristics		Complete responder group (n= 71)
Gender	Female	50/71 (70.4%)
	Male	20/71 (28.2%)
Age	Age <55 years	49/71 (69%)
	Age ≥55 years	22/71 (31%)
Type of caregiver	First-degree relatives	29/71 (40.8%)
	Second-degree relatives	24/71 (33.8%)
	School caregivers	18/71 (25.4%)
Level of education	Higher education	61/71 (85.9%)
	Secondary school	10/71 (14.1%)
Type of training session	Live	35/71 (49.3%)
	Digital	36/71 (50.7%)

Table 2: results total score of knowledge and subgroup analysis. All values are expressed as medians, with the interquartile range Q1 to Q3 in between brackets.

		Pre-training Knowledge median (Q1; Q3)%	Post-training Knowledge median (Q1; Q3)%	P-value
All participants (n = 71)		66.7 (58.3; 75)	83.3 (75; 91.7)	**P < 0.001**
Age	<55 years	75(66.7; 79.2)	83.3 (83.3; 91.7)	**P < 0.001**
	≥55 years	58.3 (58.3; 75)	75 (66.7; 83.3)	**P =0.004**
		P = 0.030	**P= 0.005**	
Type care giver	First-degree relatives	75 (58.3; 83.3)	83.3 (83.3; 100)	**P < 0.001**
	Second-degree relatives	62.5 (58.3; 75)	75 (66.7; 83.3)	**P = 0.003**
	School caregivers	66.7 (66.7; 75)	83.3 (75; 83.3)	**P = 0.004**
		P = 0.056	**P = 0.003** *POST hoc (2nd<other groups; p<0.001)*	
Level of education	Higher education (master's degree)	75 (58.3; 75)	83.3 (83.3; 91.7)	**P = 0.027**
	Higher education (bachelor's degree)	66.7 (58.3; 75)	83.3 (75; 83.3)	**P < 0.001**
	Secondary school	58.3 (50; 77.1)	79.2 (58; 91.7)	**P = 0.002**
		P = 0.355	P= 0.487	
Type of training session	Live training session	75 (66.7; 83.3)	83.3 (75; 91.7)	**P<0.001**
	Digital training session	66.7 (58.3; 75)	83.3 (75; 83.3)	**P<0.001**
		P=0.024	**P=0.013**	

session on knowledge level has been less well studied.

We noticed that every subgroup (age, education level, caregiver and session type) showed a significant amelioration in the total knowledge score and self-efficacy. Overall, this implies that the training is valuable for all kinds of caregivers, also for the parents who received information directly from the allergy pediatrician at time of diagnosis. This is in line with the EAACI Food Allergy and Anaphylaxis Guidelines in which repeated education is advised (8).

The high median total score of knowledge (66.7%) before the training of both partial and complete responders was in stark contrast to what one might expect. A previous study about knowledge on asthma, food allergy and anaphylaxis in a group of university students, school teachers and parents of asthmatic children, showed a low knowledge level on food allergy and anaphylaxis (17). The higher scores in our study can be attributed to the participants' level of education and the extensive information all parents received from the pediatrician and dietician at the time of diagnosis (max 3- 4 months before the training session). The significantly higher knowledge score in the younger group may be due to the large proportion of parents in this group.

The high median total score of self-efficacy (80%) before the training session in the partial and complete responder group corresponds to previously published studies showing a high level of health literacy within a population of caregivers of food-allergic children. Caregivers participating in these research studies are more college-educated, middle or higher socio-economic status caregivers, that are presumably less likely to have poor health literacy (18). In addition the high total score of self-efficacy before the training session might be as well explained by the short time between the individual and group training session. The high level of self-efficacy before the training session is in disagreement with the Belgian KCE study (13). The much higher self-efficacy score in our population may be due to the selected group of Dutch speaking, higher educated and predominantly first degree relatives who received extensive information at diagnosis.

The most important study limitations were the one center patient recruitment, the Dutch translation of a validated questionnaire, the fact that the self-efficacy questionnaire was designed for school caregivers only and the voluntary aspect.

In contrast to most European countries allergologists are not recognized nor have a specific title in Belgium (19). Therefore, funding of referring these patients for those time-consuming therapeutic educational sessions is also lacking. Given the here proven efficacy of these sessions, we would like to advocate for their reimbursement, which might be most efficient by introducing a recognition of (pediatric) allergologists in Belgium as (sub) specialty. By extension, it would even be potentially life-saving if we could initiate training in all schools and allow the use of auto-injectors to their personnel after training, even in children who have their first anaphylaxis attack at school.

4.2 Conclusion

We concluded that specialized group training on anaphylaxis prevention, recognition and treatment for all caregivers of children with IgE-mediated allergy at risk of anaphylaxis on top of standard care, significantly improves the total score of knowledge and self-efficacy of all the caregivers. This group training on anaphylaxis should become a part of standard of care. Investment in repeated education for all caregivers might improve both level of knowledge and self-efficacy and could prevent accidental exposures and severe anaphylactic reactions. This might reduce emergency care admissions and hospitalizations, which might result in lower medical costs.

Acknowledgments

We would like to thank Yves Vandekerckhove and Pieter Vandekerckhove for their comments and support and Koen Huysentruyt for his contribution in the statistical analysis of this study.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.. All caregivers in this research participated voluntary the training sessions and the training sessions were free of charge.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

REFERENCES:

1. Ramsey NB, Guffey D, Anagnostou K, Coleman NE, Davis CM. Epidemiology of Anaphylaxis in Critically Ill Children in the United States and Canada. J Allergy Clin Immunol Pract. 2019;7(7):2241-2249. doi: 10.1016/j.jaip.2019.04.025
2. Nagakura KI, Sato S, Asaumi T, Yanagida N, Ebisawa M. Novel insights regarding anaphylaxis in children - With a focus on prevalence, diagnosis, and treatment. Pediatr Allergy Immunol. 2020;31(8):879-888. doi: 10.1111/pai.13307
3. Muraro A, Roberts G, Worm M, Bilò MB, Brockow K, Fernández Rivas M et al. EAACI Food Allergy and Anaphylaxis Guidelines Group. Anaphylaxis: guidelines from the European Academy of Allergy and Clinical Immunology. Allergy. 2014;69(8):1026-45. doi: 10.1111/all.12437
4. Muraro A, Clark A, Beyer K, Borrego LM, Borres M, Lødrup Carlsen KC et al. The management of the allergic child at school: EAACI/GA2LEN Task Force on the allergic child at school. Allergy. 2010;65(6):681-9. doi: 10.1111/j.1398-9995.2010.02343.x.
5. Worm M, Moneret-Vautrin A, Scherer K, Lang R, Fernandez-Rivas M, Cardona V et al. First European data from the network of severe allergic reactions (NORA). Allergy. 2014;69(10):1397-404. doi: 10.1111/all.12475.
6. Muraro A, Mendoza Hernandez DA. Managing food allergy and anaphylaxis: A new model for an integrated approach. Allergol Int. 2020;69(1):19-27. doi: 10.1016/j.alit.2019.10.004
7. Knibb RC, Barnes C, Stalker C. Parental confidence in managing food allergy: Development and validation of the food allergy self-efficacy scale for parents (FASE-P). Clin Exp Allergy. 2015;45(11):1681-1689. doi: 10.1111/cea.12599
8. Muraro A, Agache I, Clark A, Sheikh A, Roberts G, Akdis CA et al. European Academy of Allergy and Clinical Immunology. EAACI food allergy and anaphylaxis guidelines: managing patients with food allergy in the community. Allergy. 2014;69(8):1046-57. doi: 10.1111/all.
9. Centre for clinical practice at NICE (UK). Anaphylaxis Assessment to confirm an anaphylactic episode and the treatment for a suspected anaphylactic episode and the decision to refer after emergency treatment for a suspected anaphylactic episode. Manchester (UK): National Institute for Health and Clinical Excellence (UK); 2011 [cited 2022 Aug 16]. Available from: https://pubmed.ncbi.nlm.nih.gov/25340233 .
10. Polloni L, Baldi I, Lazzarotto F, Bonaguro R, Toniolo A, Gregori D et al. Multidisciplinary education improves school personnel's self-efficacy in managing food allergy and anaphylaxis. Pediatr Allergy Immunol. 2020;31(4):380-387. doi: 10.1111/pai.13212.
11. Boyce JA, Assa'a A, Burks AW, Jones SM, Sampson HA, Wood RA et al. Guidelines for the diagnosis and management of food allergy in the United States: summary of the NIAID-Sponsored Expert Panel Report. Nutrition. 2011 Feb;27(2):253-67. doi: 10.1016/j.nut.2010.12.001.
12. Pouessel G, Beaudouin E, Tanno LK, Drouet M, Deschildre A, Labreuche J, Renaudin JM; Allergy Vigilance Network®. Food-related anaphylaxis fatalities: Analysis of the Allergy Vigilance Network® database. Allergy. 2019 Jun;74(6):1193-1196. doi: 10.1111/all.13717.
13. Rondia K, Adriaenssens J, Van den Broucke S, Kohn L. Health Literacy : What Lessons Can Be Learned from the Experiences of Other Countries? Brussels:KCE;2020 Jan 9 [cited 2022 Aug 16]. 74 p. Report 322. Available from: https://kce.fgov.be/sites/default/files/2021-11/KCE_322_Health_Literacy_Report.pdf
14. Ozturk Haney M, Ozbıcakcı S, Karada- G. Turkish teachers' self-efficacy to manage food allergy and anaphylaxis: A psychometric testing study. Allergol Immunopathol (Madr). 2019;47(6):558-563. doi: 10.1016/j.aller.2019.03.002.
15. Sasaki K, Sugiura S, Matsui T, Nakagawa T, Nakata J, Kando N et al. A workshop with practical training for anaphylaxis management improves the self-efficacy of school personnel. Allergol Int. 2015;64(2):156-60. doi: 10.1016/j.alit.2014.10.005.
16. Gonzalez-Mancebo E, Gandolfo-Cano MM, Trujillo-Trujillo MJ, Mohedano-Vicente E, Calso A, Juarez R et al. Analysis of the effectiveness of training school personnel in the management of food allergy and anaphylaxis. Allergol Immunopathol (Madr). 2019;47(1):60-63. doi: 10.1016/j.aller.2018.05.005.
17. Urrutia-Pereira M, Mocellin LP, de Oliveira RB, Simon L, Lessa L, Solé D. Knowledge on asthma, food allergies, and anaphylaxis: Assessment of elementary school teachers, parents/caregivers of asthmatic children, and university students in Uruguaiana, in the state of Rio Grande do Sul, Brazil. Allergol Immunopathol (Madr). 2018;46(5):421-430. doi: 10.1016/j.aller.2017.09.018.
18. Ditzler N, Greenhawt M. Influence of health literacy and trust in online information on food allergy quality of life and self-efficacy. Ann Allergy Asthma Immunol. 2016;117(3):258-263.e1. doi: 10.1016/j.anai.2016.07.011.
19. Fyhrquist N, Werfel T, Bilò MB, Mülleneisen N, Gerth van Wijk R. The roadmap for the Allergology specialty and allergy care in Europe and adjacent countries. An EAACI position paper. Clin Transl Allergy. 2019 Jan 24;9:3. doi: 10.1186/s13601-019-0245-z.

Table 3: results total score of self-efficacy and subgroup analysis. All values are expressed as medians, with the interquartile range Q1 to Q3 in between brackets.

		Pre-training Self-efficacy median (Q1;Q3)%	Post-training Self-efficacy median (Q1;Q3)%	P-value
All participants (n = 71)		80 (75; 87.5)	85 (80%;92.5%)	**P < 0.001**
Age	<55 years	80 (75; 90)	85 (80; 92.5)	**P<0.001**
	≥55 years	81.3 (64.4; 85)	83.8 (79.4; 92.5)	**P=0.006**
		P=0.471	P=0.878	
Type caregiver	First-degree relatives	82.5 (75; 93)	87.5 (80; 93.8)	**P=0.026**
	Second-degree relatives	80 (63.1; 85)	82.5 (77.5; 91.3)	**P=0.007**
	School caregivers	76.3 (72.5; 82.5)	82.5 (80, 88.1)	**P=0.001**
		P=0.098	P=0.275	
Level of education	Higher education (master's degree)	80 (67.5; 85)	87.5 (77.5; 92.5)	**P=0.005**
	Higher education (bachelor's degree)	80 (75; 90)	83.8 (80; 93.1)	**P=0.005**
	Secondary school	75 (46.9; 85.6)	82.5 (77.5; 90.6)	**P=0.024**
		P=0.265	P=0.153	
Type of training session	Live training session	80 (75; 92.5)	85 (80; 92.5)	**P=0.013**
	Digital training session	80 (73.1-85)	82.5 (80-91.9)	**P<0.001**
		P=0.730	P=0.560	

Figure 1: Total knowledge score (%) before vs. after training

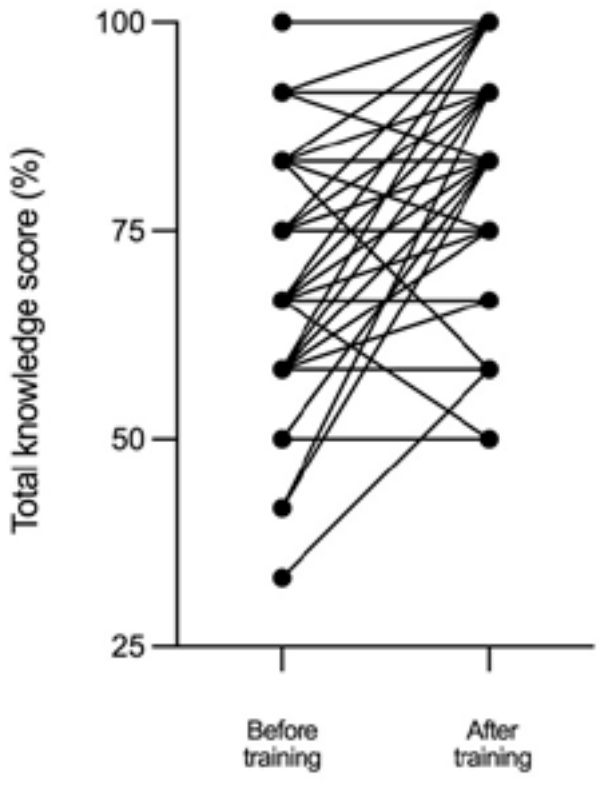

Figure 2: Total self-efficacy score (%) before vs. after training