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## WORDS OF APPRECIATION

... and here we are. This little book just gives a glimpse of the work that has been invested and all the people who made an invaluable contribution to it. I will hold dear memories of all of them.

To start with, I hold a great gratitude towards all participants of our studies. Many of them were patients in the last months of their lives who invested their precious time and energy in our studies. Thank you so much.

Clearly, I could not have done anything without people guiding me through this trajectory. In particular my amazing team of supervisors:

Prof van der Heide, dear Agnes – it has been an honour to work for and with you. I learnt so much from your sharpness, pragmatism and fine sense of humour. It seems like nothing in the world can disrupt your calmness. I appreciate that you allowed me to explore and formulate my own thoughts and conclusions.

Prof van Delden, dear Hans, I was always looking forward to our discussions about philosophy, psychology and a little bit of football. I learnt a lot from you and you really broadened my horizon. It is a pity that the time of exchanging thoughts is over.

A tremendous thanks to my daily supervisors dr Korfage and dr Rietjens, dear Ida and Judith. Setting up and coordinating the ACTION project from A to Z is quite a challenge and I have a lot of respect for how you tackled all the ups and downs of the project and juggled all demands. You always made time for me and supported me throughout this project. I learnt a lot from both of you and you really made me grow. Thank you!

Thank you to Erica, who was a perfect supervisor when I started working at MGZ. I always admired your passion for health care, the patients and their relatives.

Which brings me to the ACTION consortium – starting a PhD in this international project, with so many great minds, is a blessing. I had the best learning experience listening to all of you and it is very special to have experienced such a supportive team throughout all these years. We are just like a little ACTION-family – thank you!

Petra deserves special recognition, because she kept her head cool during all the years and was always there for us. This would not have been possible without you.

Also many thanks to Kim, who was a perfect helping hand – you are so smart and strong, you will go very far!

Special thanks to 'team Denmark', Mogens, Anna and Caroline (and the whole research group in Copenhagen), for being so kind and welcoming during my stay in Copenhagen. I learnt a lot during this short visit and had a very nice time! Mogens, I am honoured that you agreed to sit in the committee and I am looking forward to hearing your opinion on this thesis.

Our little group of juniors deserves special credits; your support was essential for me. You all work so hard and I am very proud of all of you!

My ACTION buddy Marieke – you have achieved so much and can be very proud of your work. I will miss our calls, e-mails and your encouragements, and I am happy that our conversations will continue and have shifted from inclusion numbers and articles to review, to life in general and all its wonders.

Many thanks to the participating hospitals and all employees who did their very best for our study; special thanks to the facilitators who managed to squeeze this project into their busy schedules.

Thank you to Lia for spending so much time with me screening the patient lists. It is a pity that we realized I could actually do it alone, which was the end of our meetings – luckily not a definite one! I am glad our paths keep crossing and we continue to work together.

I extend my gratitude to the other side of the ocean, Holly, Paul and Renee, and all members of the group – I had a fantastic time in New York! Holly, you are a truly inspiring leader, it is remarkable how much trust you put in people and encourage them to form their own thoughts. I learnt so much from you. Simon, I will never forget Boston, the snowstorm and your lovely family. Thank you! Katie, Rahul and Joe, you were amazing housemates and made me feel so home.

Thank you to all the co-authors and collaborators for contributing to the papers, your valuable feedback helped me grow.

My sincerest thanks to the members of the Reading Committee, Prof Takkenberg, Prof Smets and Prof Aerts, for your time and consideration of reading my thesis, and for taking part in the defence. Prof Groenvold, dr Witkamp and dr van Zuylen, I am honoured that you all agreed to exchange your thoughts with me during the defence.

The Erasmus MC is an inspiring environment and so are its employees. Tilleke, my Dutch mama, it was a privilege to learn from you. You truly are one of a kind; please never retire, every psychologist (every human being in fact!) should learn from you. Hanneke, thank you for being such a good colleague in the Psychiatry, I am happy we are still in touch.

My dear, dear lovely colleagues of the MBL group – what a great bunch of people you are! You have no idea what you all mean to me. I will always remember our meetings, social events, random talks on the corridor and your support throughout all this time. Anouk, we started together and it was so special to see you grow and succeed. Well done! Arianne, same for you, you work so hard and never forget to pay attention to the people around you. Cathy, thanks for New York and Lisbon (which was quite alright actually), Jet – Rotterdam's finest, Mirjam, Sophie and Veerle, you all mean so much to me!

Dear colleagues of MGZ, PhD life is not always easy, but as long as you were around, life was good! Many thanks to Valerie and David (for the support, sushi and *patat!*), Joost and Jeroen, Gianni,

Marcel (a perfect day in St. Louis and everything since then), Leah (for being gym buddies, without ever going ...), Jan (for all the walks through the park), Nikki, Hafez, Damir (not technically a MGZ-er but still; Paris, Paris – glad that you moved here!), Maryse (I loved seeing you grow and grow and grow, happy to have you as a friend), and many many more. Domino, Esther, Frank, Kevin, Suzette and Tiago, you were amazing roommates. The social committee, Farsia our very own leader, Rik, Veerle, Sophie, Branko, Erik – you are so much fun!

Thanks to my new colleagues at MPP and the pain department – every day I am looking forward to working with you! Special thanks to Jessica, who helped me with everything and was so welcoming and kind. Krishna, I couldn't be happier to have you as a colleague, please never start your residency so we can stay together forever!

The Persian group – thanks for all the lunches. Special thanks to Mohsen, Marzyeh and of course Amir and Yasaman. You are truly amazing.

One might forget, but there is a whole life outside of the EMC and particularly away from your loved ones, friends become your family. My girls, I am so proud of each and every one of you – I admire you all, the support and love you give, is amazing. I am looking forward to growing old with you. Jana – this PhD was worth it just because it brought us together! We went through a lot (getting lost in snow storms, sharing this US experience, champagne walks and so so many coffee meetings). I miss you a lot, your energy is radiant (Ps: could you please leave Germany and come back? Thanks). Kristina, you are the most humble, intelligent and stable person! I am happy that we started together in little Groningen and after many different places and countries we are neighbours again. I love your humour and no-nonsense point of view! Sasha, you are like my sister! I know I can always count on you, your energy and enthusiasm is contagious! You are so smart and hard working, you deserve the world.

Mahnaz and Azadeh, my Persian pearls, our coffee meetings and sharing the highs and lows of life was one of my most favourite parts of this journey. Nasim – my Persian better half on the other side of the world, I miss you! Minajoon, I am so proud of your journey, there is nothing you can't do! Nati, what was supposed to be a language exchange ended up in one of my most valuable friendships. You are one of a kind, I admire your passion and drive! I love how we stick together, through many different places and countries, and an eternal thanks to technology that lets us keep in touch no matter where we are. Florence, I have a lot of respect for how you juggle all demands in your life, you are amazing and so strong! And of course Jantje, my oldest friend, your friendship means the world to me. I admire your passion and strength, how you always seem to find a way for the impossible to work out and keep being sparkly, happy and optimistic.

My friends from my early Holland-days, Jorn and Jo-Janneke, I am so happy we are still in touch. Lianne, how special that we started in the cellars of the faculty building and look where we are now! You are doing amazingly. Vera, you inspire me and I cannot wait to start our very own practice.

Julian, for being there for me for so many years, thank you. Also many thanks to the family Gretsche for being a second home. Thanks to my friends in Germany, die Jungs, particularly Heiko, Raphael, Steffen, Hauke and Kirill (for our *Brieffreundschaft!*). Ingeborg, for being so colourful and inspiring. Ana, you were the most amazing mentor, your friendship means a lot to me and Lisbon will forever be in my heart!

I am lucky to have two very special people as my paranymphs who brighten up my world. Farsia, you are the strongest, so smart and inspiring. The world would be boring and colourless without you! Thank you for your unconditional support, it means a lot to me! Rik, you are like my little brother, but foremost the most wonderful colleague and friend. Thank you for laughing about my jokes that are never funny. I love that we share the same passion for psychology. I am honoured to have you by my side.

Thank you to the Solano family, how beautiful to meet you and being greeted with so much love. Muchas gracias.

And then my own family – to start with those that always watch and guide me. Oma, maman bozorg, baba bozorg – like no one else you taught me unconditional love, to believe in yourself and see opportunities wherever you go. You showed me that cultures and languages do not matter and that we have to stick true to ourselves and never forget where we came from. You were, all in your own way, so inspiring and paved my way. I am looking up to you, I know you are there and I miss you every day. This one is for you.

My family - the bravest of them all, you are everything to me and I am nothing without you. Ahmad, your journey is very inspiring for me, as is your indestructible calmness (and I am well aware that I will never be able to reach your level). Cornelia, Katharina and Hannah, I love how creative, colourful and full of joy you are! Azi, you are so inspiring, so sharp and smart, I look up to you. Bega, same for you (but really, Bangkok? Wasn't there anything closer?). Susu, how could I possibly describe what you mean to me? You are so supportive, cool and smart. You have achieved so much and will always be a shining example for me. Torsten, you are so supportive and genuine, thank you for always sending me postcards and taking me along your journey! My little boys, Alexi and Leo, I have seen you grow up and now you are adults (life is crazy). I am so proud of you – go and discover the world (but don't go far, ok?! Jan, my big brother, my rock, I always thought nothing could happen to me as long as you are around and it is still true even though we are far away from each other. Ich hab' dich lieb Jan! Tina, I am happy you are part of the family, you brought your very own (Badisch) light! And of course my parents, without them I would not be here. Thank you for your love and help, I know I can always rely on you. Mama, thank you for inspiring me and teaching me so much! You are amazing just the way you are. Baba, as a father, as a colleague, you mean everything to me. Your optimism is unique and your life philosophy tremendously inspiring. The world is a better place because of you.

And of course, Juan. Thank you for being there for me, for loving me the way I am and for sharing your precious time with me. You have this special capability of seeing the beauty in small things, never losing your sense of humour and supporting me unconditionally. The future is ours, te quiero mucho.



## PHD PORTFOLIO

Name PhD student:	Lea Jasmina Jabbarian
Erasmus MC Department:	Public Health
Research school:	Netherlands Institute for Health Sciences (NIHES)
PhD period:	2013-2018
Promotors:	Prof.dr. A. van der Heide (Erasmus MC) Prof.dr. J.J.M. van Delden (UMC Utrecht)
Supervisors:	dr. I.J. Korfage (Erasmus MC) dr. J.A.C. Rietjens (Erasmus MC)

### 1. PhD training

General academic skills	Year	Workload
CPO course "Patient oriented research"	2014	0.2 ECTS
Systematic literature retrieval in PubMed	2014	0.2 ECTS
EndNote	2014	0.2 ECTS
Research integrity	2015	0.2 ECTS
Didactic training – part-qualification teaching, Erasmus MC	2015	0.2 ECTS
Time and project management course for PhD students	2016	1 ECTS
Basic course Rules and Organization for Clinical researchers (BROK ®)	2016	1.5 ECTS
Biomedical English writing and communication	2016	0.5 ECTS

Research skills	Year	Workload
Master of Science in Health Sciences, specialization epidemiology (NIHES) - In depth course: Suffering, death and palliative care	2014-2016	70 ECTS

Presentations	Year	Workload
<b>Oral presentations</b>		
Respecting Choices in the Netherlands, Symposium for junior researchers in proactive palliative care, Nijmegen, the Netherlands	2014	1 ECTS
The ACTION trial, ACP Research Networking Meeting, Calgary, Canada	2014	1 ECTS
Preferences and practices of patients with lung disease and their healthcare providers regarding advance care planning: a systematic review, Congress of the Society for Medical Decision Making, St. Louis, United States of America	2015	1 ECTS
The ACTION trial, Research meeting of the Department of Public health (Erasmus MC), Rotterdam, the Netherlands	2015	1 ECTS
The ACTION trial, Pre-congress seminar of the European Association for Palliative Care Research Network & European Palliative Care Research Centre, Dublin, Ireland	2016	1 ECTS
Advance care planning in pulmonology: a systematic review of preferences and practices, World research congress of the European Association for Palliative Care, Dublin, Ireland	2016	1 ECTS
Patients' experiences with advance care planning: a systematic review, World research congress of the European Association for Palliative Care, Dublin, Ireland	2016	1 ECTS
Advance care planning in pulmonology: a systematic review of preferences and practices, Research meeting of the Department of Public health (Erasmus MC), Rotterdam, the Netherlands	2016	1 ECTS

Advance care planning, 'Post-EAPC symposium', Utrecht, Netherlands	2016	1 ECTS
Illness representations, mental health and quality of life in patients with advanced cancer, IPOS World congress of Psycho-oncology, Berlin, Germany	2017	1 ECTS
Relatieve validiteit van de EORTC item bank voor emotioneel functioneren in de internationale ACTION studie, Nederlands-Vlaamse wetenschapsdagen palliatieve zorg, Amsterdam, the Netherlands	2017	1 ECTS
Challenges face during cross-cultural research, Infant, child and adolescent research group, Department of Public Health, Rotterdam, the Netherlands	2018	1 ECTS
Assessing emotional functioning with increased power, World research congress of the European Association for Palliative Care, Bern, Switzerland	2018	1 ECTS
The stability of treatment preferences among patients with advanced cancer, Advance Care Planning international conference, Rotterdam, the Netherlands	2019	1 ECTS
Coping strategies of patients with advanced lung or colorectal cancer in six European countries: Insights from the ACTION study, World congress of the European Association for Palliative Care, Berlin, Germany	2019	1 ECTS
<b>Poster presentations</b>		
Stability of treatment preferences of patients with advanced cancer, Congress of the Society for Medical Decision Making, Pittsburgh, United States of America	2017	0.3 ECTS
Multicenter cluster gerandomiseerde trial naar de effecten van een advance care planning interventie op de kwaliteit van leven van patiënten met kanker – de ACTION studie, Nederlands-Vlaamse wetenschapsdagen palliatieve zorg, Amsterdam, the Netherlands	2017	0.3 ECTS
The stability of treatment preferences among patients with advanced cancer, World research congress of the European Association for Palliative Care, Bern, Switzerland	2018	0.3 ECTS

Conferences, seminars and workshops	Year	Workload
Weekly research seminars of the Department of Public Health, Rotterdam, the Netherlands	2013-2018	3 ECTS
Biweekly meetings of the research group Medical Care and Decision-Making at the End of Life, Rotterdam, the Netherlands	2013-2018	1.5 ECTS
Symposium for junior researchers in proactive palliative care, Nijmegen, the Netherlands	2014	0.3 ECTS
ACP Research Networking Meeting, Calgary, Canada	2014	1.2 ECTS
Research meeting 'Expertisecentrum Palliatieve Zorg', Rotterdam, the Netherlands	2014	0.3 ECTS
Erasmus MC PhD Day	2014	0.3 ECTS
Nationaal Congres Palliatieve Zorg, Lunteren, the Netherlands	2014	0.9 ECTS
Research meeting on Elderly care, Rotterdam, the Netherlands	2015	0.3 ECTS
Congresses of the Society for Medical Decision Making	2015, 2017	2.4 ECTS
World congresses of the European Association for Palliative Care	2016, 2018, 2019	3.0 ECTS
IPOS World congress of Psycho-oncology	2017	1.2 ECTS
Weekly research seminars of the Center for Research on End-of-Life Care, Cornell University, New York City, United States of America	2017	2.4 ECTS
Advance Care Planning international conference	2019	0.9 ECTS

**Grants**

Travel grant of the René Vogels Foundation (Dutch Society for Oncology)	2017
Travel grants of the Stichting Erasmus Trustfonds	2015, 2017, 2018

## 2. Teaching activities

<b>Educational activities and lecturing</b>	<b>Year</b>	<b>Workload</b>
Supervision of medical students – ‘community projects’, 3 <sup>rd</sup> year curriculum Medicine, Erasmus MC	2015-2016	4 ECTS
Lecturer ‘Lifestyle counselling and primary prevention’ 3 <sup>rd</sup> year curriculum Medicine, Erasmus MC	2015-2016	2 ECTS
Evaluating bachelor essays, 3 <sup>rd</sup> year curriculum Medicine, Erasmus MC	2015-2016	4 ECTS



## ABOUT THE AUTHOR

Lea Jasmina Jabbarian was born on the 18th of August 1989 in Lennestadt, Germany. After graduating from the Teletta-Gross-Gymnasium in Leer in 2009, she started studying Psychology at the Rijksuniversiteit in Groningen, the Netherlands. During her Bachelor programme she was selected for the *Honours College*. In 2011, she studied at the University of Lisbon, Portugal for 7 months during her Erasmus exchange programme.



In 2012 she started her Master in Clinical Psychology at the Erasmus University Rotterdam, which she finished in 2013, and was awarded the Thesis prize for the best master thesis in Psychology. In December 2013 she started her PhD at the Department of Public Health in the Erasmus MC under supervision of Prof.dr. Agnes van der Heide, Prof.dr. Hans van Delden, dr. Ida Korfage and dr. Judith Rietjens. The PhD was embedded in the international ACTION project, investigating an advance care planning intervention for patients with advanced cancer. During her PhD, she finished a Master in Health Sciences (Epidemiology) at the Netherlands Institute for Health Sciences. In 2017, she was awarded the René Vogels Travel Scholarship and worked for three months as a visiting researcher at the Center for Research at the End-of-Life at Cornell University in New York City, the United States of America, under supervision of Prof.dr. Holly Prigerson. In 2018, she worked two weeks at the University of Copenhagen, Denmark, under supervision of Prof.dr. Mogens Grønvold and dr. Anna Thit Johnsen.

In 2018 she started a new position in the Erasmus MC as a scientific lecturer at the Department of Medical Psychology and Psychotherapy and as a psychologist at the Center for Pain Medicine.



## LIST OF PUBLICATIONS

### This thesis

Rietjens JA, Korfage IJ, Dunleavy L, Preston NJ, **Jabbarian LJ**, Christensen CA, de Brito M, Bulli F, Caswell G, Červ B, van Delden J, Deliëns L, Gorini G, Groenvold M, Houttekier D, Ingravallo F, Kars MC, Lunder U, Miccinesi G, Mimić A, Paci E, Payne S, Polinder S, Pollock K, Seymour J, Simonič A, Johnsen AT, Verkissen MN, de Vries E, Wilcock A, Zwakman M, van der Heide PI A. Advance care planning--a multi-centre cluster randomised clinical trial: the research protocol of the ACTION study. *BMC Cancer*. 2016;16:264

**Jabbarian LJ**, Zwakman M, van der Heide A, Kars MC, Janssen DJA, van Delden JJ, Rietjens JAC, Korfage IJ. Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices. *Thorax*. 2018;73(3):222-230.

Zwakman M, **Jabbarian LJ**, van Delden J, van der Heide A, Korfage IJ, Pollock K, Rietjens J, Seymour J, Kars MC. Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness. *Palliat Med*. 2018;32(8):1305-1321.

**Jabbarian LJ**, Groenvold M, Petersen MA, Christensen CA, Deliëns L, van der Heide A, Kars MC, Miccinesi G, Payne S, Wilcock A, Korfage IJ; ACTION consortium. Assessing Emotional Functioning with Increased Power: Relative Validity of a Customized EORTC Short Form in the International ACTION Trial. *Value Health*. 2019;22(1):92-98.

**Jabbarian LJ**, Maciejewski RC, Maciejewski PK, Rietjens JA, Korfage IJ, van der Heide A, van Delden JJ, Prigerson HG. The Stability of Treatment Preferences among Patients with Advanced Cancer. *J Pain Symptom Manage*. 2019. pii: S0885-3924(19)30049-1.

**Jabbarian LJ**, Rietjens JAC, Mols F, Oude Groeniger J, van der Heide A, Korfage IJ. Illness representations, mental health and quality of life in patients with advanced cancer. Submitted

**Jabbarian LJ**, Korfage IJ, Červ B, van Delden JJM, Deliëns L, Miccinesi G, Payne S, Thit Johnsen A, Verkissen MN, Wilcock A, van der Heide A, Rietjens JAC, on behalf of the ACTION consortium. Coping strategies of patients with advanced lung or colorectal cancer in six European countries: Insights from the ACTION study. Under review

### Other publications and manuscripts

Korfage IJ, Rietjens JA, Overbeek A, **Jabbarian LJ**, Billekens P, Hammes BJ, Hansen-van der Meer E, Polinder S, Severijnen J, Swart SJ, Witkamp FE, van der Heide A. A cluster randomized controlled trial on the effects and costs of advance care planning in elderly care: study protocol. *BMC Geriatr*. 2015;15:87

Overbeek A, Rietjens JAC, **Jabbarian LJ**, Severijnen J, Swart SJ, van der Heide A, Korfage IJ. Low patient activation levels in frail older adults: a cross-sectional study. *BMC Geriatr*. 2018;18(1):7.

Overbeek A, Korfage IJ, **Jabbarian LJ**, Billekens P, Hammes BJ, Polinder S, Severijnen J, Swart SJ, Witkamp FE, van der Heide A, Rietjens JAC. Advance Care Planning in Frail Older Adults: A Cluster Randomized Controlled Trial. *J Am Geriatr Soc.* 2018;66(6):1089-1095.

Korfage IJ, Carreras G, Arnfeldt C; Bramley L, Briggs L, Bulli F, Caswell G, Cerv B, van Delden J, Deliens L, Eecloo K, Gorini G, Groenvold M, Hammes B, Ingravallo F, **Jabbarian LJ**, Kars M, Kodba Čeh H, Lunder U, Miccinesi G, Mimic A, Ozbic P, Payne S, Polinder S, Pollock K, Preston N, Seymour J, Simonic A, Thit Johnsen A; Toccafondi A, Verkissen M, Wilcock A, Zwakman M, van der Heide A\*, Rietjens J\* Advance care planning in patients with advanced cancer: results from the European six country, cluster-randomized ACTION trial. *Submitted*

Zwakman M, van Delden JJM, Caswell G, Christensen CA, Deliens L, Ingravallo F, **Jabbarian LJ**, Johnsen AT, Korfage IJ, Mimic A, Preston NJ, Kars MC. Content analysis of Advance Directives completed by patients with advanced cancer as part of an Advance Care Planning intervention: insights gained from the ACTION trial. *Under review*

Zwakman M, Milota M, van der Heide A, **Jabbarian LJ**, Korfage IJ, Rietjens J, van Delden JJM, Kars MC. Patients' Readiness for Advance Care Planning Conversations: a Qualitative Study as part of the ACTION Study *Submitted*