10 The History of the model; How it was developed – a personal story. Dedications

10.1 Background to developing the model

10.1.1 Developing the iCARE-Haaland training model: an overview

The work Ane Haaland had done over the last 45 years functions as the foundation for the development of the pedagogical approach to communication which is described in this manual. The development of the iCARE training model started in Siauliai TB hospital, Lithuania in 2006, as a response to the needs to improve communication with patients, expressed by leaders and providers in the hospital. The work was sponsored by LHL, the Norwegian Heart and Lung Patient Association. The model was then implemented in Latvia, Russia, Namibia, Zambia and Tanzania, all partner countries of LHL, from 2006-2008. In each country, adjustments and improvements were made in collaboration with the users. In 2008, two nurses from the Kilifi District Hospital in Kenya, Mwanamvua Boga and Jackson Chakaya, joined the training in Zambia to assess whether this training could also be implemented in Kenya. In 2009, work started at the Kilifi district hospital, Kenya, as a collaborative project between the University of Oslo (where Ane Haaland was working), and the Kilifi KEMRI programme, financed by the Wellcome Trust. Boga and Chakaya were trained as main trainers.

By the end of 2018, 350+ providers have been trained, about 200 of these are in Kilifi, where the model has been further developed to find its present form, and a strong institutional foundation has been established with M. Boga as the lead trainer. Communicating about research has been added to the training in Kenya, and also training managers in communication skills. In 2015, Boga and her colleage Hiza Dayo conducted the training process in the Gambia and trained more than 60 providers and three trainers there, over a two year period.

In 2016 and 2017, Haaland implemented an adapted version of the training model with trainee doctors in the Wales Deanery, Cardiff University, in collaboration with professor Debbie Cohen.

Several participants in Kilifi have made changes to how their wards function, in collaboration with their managers: Their new skills have made them see their work in new ways, and removed the fear of taking initiative to change, or to talk with their managers. Many of them comment that “people change systems”, and that they want to contribute to doing this. Some of these former training participants may contribute or take initiative to a change from the bottom up – a change which so many health systems say they need and want, but for which there is no universal or cultural recipe.

10.1.2 The evolution of the model: A personal note from the author

I would like to share with you the story of how this model came to life, and show how the work with the model has provided an arena for bringing learning and insights from 45 years of working with communication in 30 countries, together to a coherent whole. It has been an amazing journey of mutual learning across cultures and professions, and – the most special has been to experience how the issues around emotions are so common to us all, and – that the learning about it brings out such joy, and gratitude.

The starting point in Tanzania: Anger, and conflict

I was in Tanzania with LHL in 2006 to find out how to help empower TB patients with knowledge and skills to handle their disease better. Many patients stopped taking their medicines too early, and there was a large problem with defaulting, and later – relapses, and development of resistant TB.

After talking with several patients, I met with the health providers - doctors and nurses, whom the patients complained strongly about, to hear their views of the situation.

"Angry patients", said the providers, when we asked what they saw as their biggest problems when dealing with TB and HIV+ patients: They did not know how to handle them, and often ended in arguments that left both parts exhausted, problems not dealt with, and HIV tests not carried out[122]

In other countries LHL worked, conflicts were common between leaders and providers, between colleagues, and between providers and patients. There was often a strong reluctance to relate to and to treat very sick and dying TB patients. Providers often blamed and shamed mothers who came to the hospital with a child who carried charms from a traditional healer, or who came late – when the child was very sick. They shouted at or used harsh words with patients who voiced their frustrations or fear when dealing with a hospital or clinic system they did not understand, and which they felt did not respect them and did not meet their needs. Many providers used angry power to "get patients to behave".

The common theme to these problems is – ***management of emotions***: Providers' own emotions, and those of the patients. I soon discovered that "emotions" was almost a dirty word among providers – emotions were to be controlled and ignored and were judged harshly. They were seen as a disturbance: "She is just being emotional" was a statement indicating a "difficult patient" with an unimportant reaction that just had to be controlled, often by using blame, sarcasm or anger.

Exploring solutions: Dealing with anger and conflict

In Tanzania, I created a one day's exploratory course on "Dealing with anger", to respond to the providers' expressed immediate need. Using role-plays, exercises, interactive group work and short lectures, a group of 20 providers learnt that behind anger is very often fear. They were surprised, but – felt it made sense when exploring their own reactions to the anger they faced from TB patients who refused to take an HIV test: The providers also felt fear when faced with an angry patient, and covered it up with using their own anger, and power.
The "picture" of two scared "children" shouting at each other brought home the idea of how seemingly impossible it is to communicate well in such situations. The emotions take up all the space.

I taught them the basic skills in emotional intelligence: To recognise and acknowledge the patient's as well as their own emotions, to analyse what happened, and to take action based on this understanding. Thus, the providers learnt:

- To recognise and acknowledge their own fear when they met with and angry patient;
- To use their knowledge to analyse the situation – that behind the patient's anger was also fear (of possible death, related to being possibly HIV positive);
- To take a step back from their automatic reaction (often anger), and then
- To meet patients' fear with respect, kindness, sincere listening and compassion.

The health providers used guided observation and reflection tasks to continue developing awareness of how they communicated with patients. The providers responded well to the new skills and reported – 6 months later – that they now had hardly any problems with their patients: Almost all the TB patients (more than 80%, according to providers' own estimates) now agreed to take the HIV test, compared to almost no one (about 20%, same estimates) before they did this training. The providers wanted to learn more – they had discovered the importance of recognising and managing emotions.

[122] TB and HIV: *There was 70% co-infection in many African countries in 2006 – if you have TB, you are 70% likely to also be HIV positive, so there is a need for TB patients to be tested for HIV. At this time in Tanzania, most TB patients (80%) refused to be tested for HIV*.

Full course taking shape in Lithuania: We (my colleague from LHL and myself) then went to the TB hospital in Siauliai, Lithuania, at the invitation of the director, a progressive medical doctor who wanted her staff to learn to communicate better with patients. Twenty members of her staff (medical doctors and nurses) had responded to a needs assessment survey I created, and a small group of them participated in formulating the first programme.

The director, who had been trained in the Russian authoritarian style, participated in the sessions, and frequently used her customary power to speak in the plenary sessions without asking permission. Stopping her respectfully and asking her to follow rules we had agreed, that everyone asks before speaking, caused everybody to hold their breath for a moment – until she laughed and said – "of course"! She was also there to challenge old ways of communicating, she said. Participants then relaxed and appreciated her.

On day 2, a conflict between the director and a line manager came to the surface – the line manager had taken the "licence to speak her mind" literally, and the two giants made the room boil with tension as they described their views, laced with heavy judgments and blame, standing up in full force in opposite parts of the room. I let it boil for a while, then stopped them respectfully, and asked if we could explore what was behind the conflict, and use the situation for everybody to learn from. I had everybody's full attention, and complete silence.
The two "combatants" agreed, after some consideration.

The explorations brought out a number of emotions on both sides, emotions that had been allowed to build up because they had not been acknowledged, respected and dealt with in a constructive way. We worked to listen to the reasons behind the strong feelings, on both sides, inviting empathy, compassion and understanding for how the two leaders saw the situation. Although some sore feelings surely remained on both sides after the session, the "air" in the training group had cleared, and the open and respectful way of dealing with the conflict had been an eye-opener.

We continued to use the lessons from this event to explore other issues, and to communicate with awareness. I revised the plan for the next day's lesson every evening, based on what had happened in the group: The curriculum was being formed, and a core element in all sessions was – recognizing, acknowledging, understanding and handling emotions – with respect.

The response to learning to recognize, understand and manage emotions was similar in all countries where we later implemented the model: This was knowledge they needed, and they did not know they needed it until they received it. Initial reluctance to deal with emotions was soon replaced by experiences and insights that showed them the power of awareness, and the strong positive effect of being able to manage their own emotions – and to recognize, respect and respond well to the patients' emotions as well: Inviting empathy with patients' fear and frustrations rather than judging them for "being emotional and difficult".

Scepticism from managers and leaders was and is there, but much of it turned into acceptance and appreciation when they saw the results of the changes – on the providers themselves, and on the patients. Several managers also participated in the courses and became strong advocates for the communication approach – in addition to radically changing their own supervision style.

Health professionals: Lack of training in management of emotions leaves a "black hole"

During my participation in the conference on person-centred medicine in Geneva (May 2010), I asked some of the many good professionals gathered there about reasons for the apparent "black hole" in the literature about training providers to deal with their own as well as patients' emotions. All acknowledged that the "hole" exists, and reasons suggested were mainly that a majority of the

medical professionals thought themselves intuitively capable of communicating well and dealing with patients' emotions and coping with their own, despite increasing evidence to the contrary. An editorial in the BMJ on "Communications and emotions" confirms this view. All of the participants I talked with acknowledged a need for more research and attention to the field of training providers to recognize and deal better with their own emotions, as well as those of their patients. As I have continued to present results from our work in national and international conferences, the response has been the same: *There is a need for research and training on providers' recognition, understanding and management of emotions, and there is a lack of training materials in this field.*
In the last couple of years, there has been increasing attention to the effects of emotional labour and to the need for emotional competence among health professionals. Furthermore, the perception of vulnerability as weakness has been strongly challenged, first and foremost by the American scientist Brene Brown – see chapter 2. The professional world is slowly getting ready to learn more about emotional competence.

So – what is so special about this learning?

The iCARE-Haaland model is complex, but the main elements are quite straightforward – starting with the need for the provider to decide that she wants to learn to communicate better. Then, the key elements are:

- Guiding users to ***discover*** their learning needs, through self-observation and reflection over time;
- ***Meeting these felt needs*** in the training workshops;
- ***Providing a realistic time frame*** - giving space for self-determined change;
- Providing a ***safe learning environment***, where failing is common, expected, and – is seen as creating situations to learn from;
- Using a methodology that ***respects the learners*** and starts where they are – in their practical day to day work, with their present skills and behaviours;
- ***Seeing emotions as a natural and positive part of life*** to be expected and managed, both in relation to providers' own emotions, and those they meet in patients and colleagues;
- Acknowledging, valuing and building on their experiences, and ***empowering*** them to take ***responsibility for their own learning;***
- Guiding them to become aware of and further develop their ***own authentic communication style*** – which feels natural, and will therefore be sustainable;
- ***Encouraging interactive reflection*** with colleagues who experience the same kinds of challenges, thus creating ***common goals*** within the training group: strengthening self-awareness, improving collaboration with colleagues, and improving patient-centred care;
- ***Having trainers who role-model respect, kindness, compassion and care,*** with curiosity and skills to explore reasons for present problems – without judging the person in action.

As both trainers and participants are emotionally present with each other, are non-judgmental, and share a common goal, a remarkable ***give-and-receive exchange of energy*** builds during the sessions. As a result, neither group becomes exhausted. Later, after having applied the methods described in this model with patients, participants report that this practice helps increase the satisfaction and enjoyment they find in their work while also lowering their risk of becoming burnt out.

The challenge is to apply all of this to the **relationships** that are central to good health care – the relationships providers have with patients, with colleagues, with communities, and – with themselves. With awareness and practice, this becomes easier, and the good results encourage the providers to continue using the skills.

The personal contribution of the author: A professional mix of skills and experience

I am not a health provider myself, and therefore had no fixed idea about what the training should look like (*although having run many training courses for health providers in a number of countries, I had experience to draw from*). I could be open to ideas without being bound to any single training models. I could simply look for what works, for what was relevant to them and which methods would inspire them to learn – in close collaboration with nurses and doctors who lived with the problems every day. Providers are busy practical people and would only change if they saw the new skills as working better than the old ones. We had the same clear goal: ***Strengthen skills to communicate and collaborate with colleagues and patients, and build skills to recognize and respect emotions – their own, as well as those of colleagues and patients.***

My first profession as a journalist had stimulated my curiosity and critical thinking and gave me techniques to explore these issues. **My second career** as a social scientist and international development worker added knowledge about cultures, context and challenges in health systems and with health personnel, as well as about research. I have worked internationally since 1975, for UN organizations, NGOs, universities and other groups, as a trainer, researcher, project developer, analyst, photographer and writer. I have worked in some of the poorest and toughest parts of the world, but also in modern well-functioning hospitals in Europe. When I started work as a UN volunteer with UNICEF in Nepal in 1975, 70% of the children in certain parts of the country died before they were 5 years old. I hit a steep learning curve then, with a clear focus on finding out which efforts worked, and why. There was no time for inessential nonsense.

I had a boss and mentor - Hallvard Kuløy, who was UNICEF Representative in Nepal and hired me for the job there - with a philosophy he expressed clearly to the staff: "*I will not criticize you for trying new things or methods, and failing – but if you don't try, you will have trouble with me!"*
We tried a lot, failed a lot and learnt a lot, in a working environment Kuløy described as "creative anarchy". I learnt the language, and started learning from my Nepali colleagues, who taught me many lessons during the eight years I worked in this beautiful country. I also did my first piece of systematic research then – to find out how people with low literacy skills interpreted drawings and pictures. We used the results to develop effective educational materials and developed a manual to share these methods with others[123].

During my years of professional work in health communication in Asia, Africa, Latin America and Europe, I have trained a number of different groups in the use of communication skills. The training often did not respond to the needs of the users, but rather to the needs of their bosses: **They** defined the need as "lack of communication skills among providers," to which the "obvious" solution was: skills training to learn better communication. To ask what the health providers felt they needed, and what the reasons were for their treating patients in rather "rough" ways, was not deemed necessary. It was not even mentioned as a valid concern: health workers were by "design" obligated to care and expected not to ask for anything but salary in return. The prerequisites for the providers to be motivated to give good care were not addressed, and the managers did not pay attention to emerging research on the subject. Now, several decades later, the knowledge about "what works" in communication skills training is readily available to any planner with a will to investigate the issue. Still, much communication training is carried out "the old way", expecting medical and nursing students to learn to communicate better by being told, through lectures and discussions, ***what*** they have to do, but very little about ***how*** to do it. Results are often as could be expected: no, or limited, improvement in communication skills. When travelling to countries across the globe, most of the

[123] Fussell, D and Haaland, A (1976): Communicating with Pictures in Nepal. UNICEF and National Development Service and Haaland, A (1983): Pretesting Communication Materials. UNICEF, Burma

providers I have met have complained about lack of communication skills: The awareness about the need for good training, and for training to manage emotions, continues to increase.

Joining hands with doctors and nurses: Action research to develop the model
The work took a new turn when I started working directly **with** the providers, rather than responding to managers' requests to conduct courses **for** them. By listening to what they felt were the problems they faced, and exploring and analysing the problems together, the training became a collaborative project that transformed the work – and the results. The providers defined the situations they struggled with, through observation and Reflection-IN-Action (RiA), the powerful method that also included the (often raw) emotions and reactions involved. We could deal with "the real thing", and the authenticity, sincerity and down to earth quality this gave the work, was precious.

There was no bullshit. No possibility to discount the training. It was about their work.
To this, I added my knowledge about communication, and gradually about emotions – I am no psychologist, but have worked extensively in the psychology field, both professionally and personally.

In 2008, Mwanamvua Boga joined a workshop in Zambia together with her colleague Jackson Chakaya, both nurses from the District Hospital in Kilifi. From an initial scepticism to the work, Mwana slowly embraced the methods and gradually made them her own: When we ran the first training course in Kilifi in 2009, Mwana and Jackson started their education as trainers. We ran one course per year in Kilifi, and Mwana gradually took charge of the training, and brought in her own experience and ideas. With Mwana on the team, we collaborated to shape the modules to their present form. Mwana has gradually introduced the work into a number of different fora, at her own initiative and/or in collaboration with her colleagues in Kilifi. I have remained a mentor to the process, and the collaboration with Mwana has an important impact on the work.

In 2015, I started collaborating with Debbie Cohen, an occupational therapy professor who invited me to develop a project with her to train their trainee doctors, using my method. We ran two courses, in 2016 and 2017, with very good results.

During the years of working with this manual, some of the aspects of our training have been gaining momentum in the research and literature in the communication field: In patient-centred care, the dimension of provider – self-relationship has been acknowledged as a very under-researched and under-focused area which is of crucial importance to the provider practicing good PCC. Our model offers a strong training focus on this aspect. The focus on emotional labour is a similar case – it has just recently been acknowledged as having crucial importance for nurses especially, and – there are few resources available to train them to handle the emotional challenges of their work.
Emotional Intelligence (EI) has furthermore gained attention as a set of skills that especially leaders need, and leaders with good EI skills have been shown to get better results for their businesses. In health care, EI is gaining increasing attention and recognition. Although the concept of EI was only included in the model from about 2015, I have added it in: What we have been teaching for years is essentially EI skills – just under a different heading. I have thus included the concept where it is natural.

Serious illness in my close family from 2012-2016, and the subsequent process to cope with my husband's death has slowed the work to complete this manual. It has also given me an opportunity to experience how a number of different providers in the Norwegian health system handle difficult emotions related to terminal illness. We have met providers with empathy and presence who made us feel seen and appreciated as fragile human beings, providers who accept tears and impossible

questions with compassion, kindness and patience. These doctors and nurses have enabled us to cope better with the situation, and we are very grateful to them. We have also met providers who give bad news by showing us the X-ray of the growing tumours on the computer without even asking my husband how he is when coming in to get the results of a brain scan, with no empathy and no time for dealing with the shock. Others have "hidden" behind statistical facts about a bleak chance for survival beyond X years, the news being delivered with a smile. We have been shocked and angered. The range of methods used to deal with emotions, and the lack of skills to do so, may be as large in the Norwegian medical system as it is in the UK, Eastern European countries, and in Africa.

Finally, my work during the last couple of years has had an increasing focus on vulnerability as a central concept which health providers need to improve their skills on – also fuelled by the experiences of being closely involved with terminal illness. In the model up until then we have worked with the concept of insecurity, and on skills to recognize and handle these emotions.
I discovered during the three years I accompanied my husband through his illness that the medical approach to vulnerability was largely ignoring it as an issue affecting the providers, and seeing it as a weakness.

We included vulnerability as a topic with the trainee doctors in Wales, and from an initial surprise and reluctance to discussing it, the two groups of young doctors learnt the positive gains from recognizing and integrating the management of their own vulnerability as an important part of their practice.

- *«I feel a heightened sense of awareness of my own emotions. I recognize emotions like anxiety and vulnerability and try to find the triggers and manage them. It is a life long learning as different situations can challenge me in different ways but this journey of discovery is an exciting one.»* *Participant, Cardiff*

I have challenged the medical views on vulnerability and shared the positive results of our training in Wales, in professional conferences in Australia, Singapore and London in 2018, and the awareness and interest in vulnerability as a central concept for medical professionals, is increasing. Much inspired by the work of the American scientist Brene Brown, this work will be a continued focus for me in the years to come.

The development of the iCARE-Haaland training model has been an exciting journey of discovery, in collaboration with good colleagues. It has been fuelled by curiosity and by the determination to get to the core of the problem and then deal with it, in collaboration with those who experience it. The model is a product of 45 years' professional work in 30 countries and is the most important work I have engaged in during my long career. Everybody who was involved in the development of the model felt somehow "right" about the structure and contents of the learning process, although many have questioned the complexity and length. As the writing has progressed, other work has been published which has supported the findings from working with the model.

Throughout the years of working with the model, as I have experienced providers struggling with making sense of death, cruelty, difficult working conditions, unrealistic or unkind managers, babies who die and patients who have lost hope – my respect for them has increased steadily. Thus, this manual is primarily dedicated to them all, with the hope that the methods here will be made available to many and help make their lives a bit easier.

10.2 Acknowledgments and Dedications

I have never before dealt with such motivated learners as those I have met when working with this model in its current form: At the time of the first workshop, they knew what they wanted to know, and how they would use the new skills in their work. There was no resistance to learning, but rather

an impatience to learn - which makes the teaching a joy. The learning process somehow gave them energy, and also energized me as the trainer. During the first workshop at the TB hospital in Siauliai, Lithuania in 2006, one of the participants drove me back to the hotel after the day's sessions, and reflected, surprised –

"I am going home to do some more reading and work on these topics. It is strange, after a long day's learning, I am not tired. Usually, after workshops I am quite exhausted."

Dedications to leaders and trainers: Manuals evolve through cooperation

Some of the best work I have done has been where I spent many years working on a communication method until it was ready to be published in a manual. ***My main learning has been: Quality work takes time, and – the close involvement of and cooperation with the users is the key element.***
I have been lucky to work with leaders who understood this and let me use the time needed to write the manuals (see ref list).

This manual is thus also dedicated to the progressive leaders and researchers who believed in the communication training model and supported me to develop it further:

- **Mette Klouman**, the leader of the international section in the Norwegian NGO (LHL), asked me in 2006 to help them develop communication interventions to support TB patient empowerment. She was open to the suggestion that we needed to work with the health providers' communication skills and attitudes, if we were to make a real impact on the patients' knowledge and skills to deal better with their TB and HIV infections. I worked with the LHL team and their partners in 6 countries for three years; (*In addition, we developed educational materials with the TB patients, to meet their need for information, see ref list*).
- **Dr Vita Globyte**, the director of the TB hospital in Siauliai, Lithuania, wanted all her staff to learn better communication skills, and used her creativity to become the first institution to run this training, as well as to support 5 of her staff to become trainers;
- **Several other leaders** welcomed the training of their staff and contributed to the development of the model: **Dr Vaira Leimane** in Latvia, **Dr Nina Nizovskaya** in Arkhangelsk, Russia, **Dr Neema Kapalata** in Temeke, Dar-es-Salaam, Tanzania, **Sister Nerumbo,** the regional TB coordinator in Windhoek, Namibia, and **Alick Nyirenda** of CHEP, Zambia. These training courses were all supported by LHL.
- In 2009, **Dr Vicki Marsh** in KEMRI-Wellcome Trust Research Programme in Kilifi, Kenya, applied for and received a grant from the Wellcome Trust to implement the training in Kilifi District Hospital, with her as the PI. Two of the hospital nurses, Mwanamvua Boga and Jackson Chakaya, had participated in the training course I conducted in Zambia, and decided to bring the training to Kenya. A number of research projects are implemented in the Kilifi hospital, and "Communicating about research" was added to the model in collaboration with Vicki and **Dr Sassy Molyneux,** and with course trainers. The model has been further developed and found its present form during the first six years (2009-2015) it was implemented in Kilifi. Vicki has been the "Godmother" of the model and supported the development throughout these years.
- **Sassy Molyneux** has collaborated with me on developing communication strategies and materials in Kilifi since 1993, when we created the concept for the first communication training approach for the fieldworkers. The manual describing this approach[124] took eight years to develop, and the present manual also builds on the work done during this period. Sassy has taken the initiative to support the completion of the manual, and get it published.

[124] Haaland, Ane and Molyneux, Sassy (2006): **Quality Information in Field research. Training manual on practical communication skills for research field workers**. WHO/TDR

- **Vicki Marsh and Sassy Molyneux** took initiative to have the training course evaluated by independent external evaluators in 2011. The report from the evaluation is referred to in several places throughout the manual, and essentially confirmed the conclusions drawn from participants' self-reported materials.
- **Dr Debbie Cohen** invited me in 2015 to come to Cardiff, Wales to implement the model with trainee doctors, based on a presentation of the work in Kenya and other countries at a medical conference in Greece.

Five trainers have been especially important in shaping the contents of this work, see the Prologue.

It has been a privilege to carry out this work, and I want to thank everybody who has been involved and made it possible – especially Mwana, who has burnt endless litres of "midnight oil" to dive deeper, question herself and others – including me – with respect, and having joy in working with these skills and see the fruits of the work when participants, as they emerged to communicate with awareness and to enjoy their work more – and become better colleagues.