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How to link health research to policy makers, practitioners and patients Use of Dutch health services by non-Dutch patients

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ABSTRACT

This article presents experiences with research-related implementation activities in the field of intercultural communication in palliative health care in the Netherlands. It is argued that sharing research aims with relevant stakeholders, organizing resulting feedback, translating findings into educational programs and other products that suit the needs of policy makers, practitioners and (immigrant) patients will facilitate the implementation process.

How can researchers bring health research findings to policy makers, development workers, activists, and community members? Health research is often conducted in settings where people are confronted with interventions designed to improve their living conditions or to influence patterns of behaviour that may be detrimental to their well-being. Although many researchers intend to influence decision-making, they often recognize, during or after their work, that their intention has not been realized. In this contribution I will share my experiences in this area. As a researcher acquainted with implementation activities, I felt challenged by the invitation to elaborate on my experience linking research to health care practitioners and patients. I tried to consider what steps we took to influence implementation and how these corresponded with existing theories. Although implementation is not a new phenomenon, the 'science' of implementation has been recently reinvented due to requests by public research funders for an accounting of the implementation results not only on paper, but also in practice (Ravensbergen et al. 2003). Funders question researchers about the expected benefits of their research, referring to scientific theories of innovation and diffusion processes (Rogers 1995) and implementation strategies (Grol 2001; Grol et al. 2007). A growing number of researchers in health care studies collaborate with relevant stakeholders in the first stages of their research projects. They want to share the objectives of their research with professionals and patients and justify their research proposals by depicting how they plan to cooperate with these groups in the process of formulating the right research questions (Caron-Flinterman et al. 2006; SerranoAguilar et al. 2009). Others recommend sharing

insights during several stages of the research process; stakeholders might contribute to determining research questions, designing the protocol design, acquiring funding, implementing methodology, interpreting results and disseminating those results to the professionals responsible for policy and practice (Thornton et al. 2003; Swaans et al. 2009). These authors recognize that a coalition of researchers and stakeholders creates two interconnected paths: ongoing development of scientific knowledge and ongoing political change. Schofield (2004) described how processes of learning and translation of strategic policies into operational activities are intertwined in this coalition. The Cochrane topic group for Effective Practice and Organization of Care (EPOC) published an overview of interventions designed to improve health professional practices (Haines 2004). Their work shows that barriers to change may exist in the health care system, the health care practice, the educational, social and political environment, in the practitioner and in the patient. Every barrier may be perceived as a lever for change (Haines 2004). In the same way attempts to link health research activities with practical interventions might contribute to the development of scientific knowledge of implementation processes. In this article I will first describe the research project and its implementation activities, followed by a reflection on the possibilities for other researchers to learn from our implementation experiences.

RESEARCH PROJECT

Some years ago we investigated why patients with a Turkish or Moroccan background in the Netherlands make little use of home care even when they are terminally ill (De Graaff & Francke 2003). Earlier research findings suggested that this limited utilization was due to the patients' unfamiliarity with the Dutch home care system (Beljaarts 1997; Mariavelias 2000), or feelings of shame and honour in the immigrant communities, or financial constraints (Van Toorn 1994; Yerden 2000). Home care service providers argued that they should adapt their services to these new clients in order to respond to reports that elderly immigrants suffered from care problems, e.g., decubitus ulcers (Van den Brink 2003) and that close kin of these terminally ill patients were overburdened (Yerden 2004). Our qualitative research in 2000-2002 with twenty families identified obstacles to Dutch home care use by patients with Turkish or Moroccan backgrounds on various levels: 1) on the patient level – lack of understanding of illness and cause of death, 2) on the family level – complexity of family structure, decision-making patterns, values and standards of care, 3) on the community level – limited care for the patient and family and significant pressure from the community to stick to traditional values, 4) on the institutional level of the Dutch health care organizations – limited information and little or negative experience with home care. These factors increased or decreased in influence depending on the main barrier – a patient's preference for care by family members. Families who had been using home care were pleased with the equipment they received, such as movable beds, decubitus mattresses, and wheelchairs and were satisfied with the support from the Dutch home care personnel. Families who had not been using Dutch home care argued that they were not adequately informed (De Graaff & Francke 2003). Therefore, our second research project in 2003-2004 included a survey of the perspectives and experiences of Dutch general practitioners and nurses regarding the discussion of available home care with families with a Turkish or Moroccan background. Do general practitioners hesitate to refer these

immigrants to Dutch home care? What is their view on the barriers to Dutch home care? The survey revealed the experiences of 78 general practitioners and 93 home care nurses, who had recently cared for a terminally ill Turkish or Moroccan person. The data confirmed many results of the first study, but, according to the Dutch professionals, communication problems were the main barrier (De Graaff & Francke 2009). We concluded that a third research project on the communication between Dutch professionals and terminally ill patients with a Turkish or Moroccan background and their families was needed, in order to better understand the gap between the patients (who felt inadequately informed) and the professionals (who felt blocked by communication problems). So the aim of our third research project (2007-2009) was twofold. First to gain insight into the decision-making and communication between the various health care professionals and the patients with a Turkish or Moroccan background and their family members in regard to oncologic palliative care. Second, we wanted to develop recommendations and instruments to improve decision-making and communication in such a way that the various health professionals as well as Turkish and Moroccan patients and their family members could make choices together that were acceptable to all parties. The challenge for us as researchers was to create a research design that would be useful for this purpose. We proposed performing a qualitative research project using thirty care cases to interview Dutch health care professionals, Turkish and Moroccan patients and family members who were all involved in the same case. Our hypothesis was that all people involved in the care of a terminally ill Turkish or Moroccan patient would cherish certain norms and values, but that sometimes they would not share these with others in the care setting. Our hope was that discovering relevant key concepts that connect the values of these families to the values of the professionals might help all parties to unite in a common decision-making process. Thus, our research questions for the third research project were: – What experiences and perceptions do Turkish and Moroccan cancer patients, their families, and the various health professionals have in regard to the care delivered in the palliative phase of a terminal illness? – How do these distinct experiences and perceptions interact (overlap, conflict, etc.)? – What are the consequences of conflicting perceptions for communication and decision-making in palliative care? We found that Turkish and Moroccan patients' relatives and their Dutch professional carers have indeed somewhat different views on 'good palliative care' and on 'good communication in palliative care'. For example, families of these patients want to get a lot of information, but they often feel that the patient should not have this information to avoid discouraging him/her. Dutch practitioners on the other hand prefer to communicate with the patient and not with his/her relatives. See Table 1 for a description of possibly conflicting views.

[TABLE 1]

But we also found that Turkish and Moroccan patients, relatives and Dutch health care professionals have many values in common and most of them want to understand the values of their partners in the decision-making process. For example, Dutch care professionals generally prefer to inform their patients about their diagnosis and prognosis because it facilitates common planning, but they also consider hope essential for the patients' spirit. The identified differences are not absolute, but more subtle and fluid.

SHARING THE RESEARCH OBJECTIVES

In the third research project four phases of activities linking research to practice can be identified. The first phase included our contacts with policymakers, practitioners and patients to share the objectives of the research and engaging with these groups to formulate appropriate research questions. We sent our research proposal to ZonMw (The Netherlands Organization for Health Research & Development) because they had launched a research program with a goal to improve palliative care for terminally ill patients and their families through research and development activities in the Netherlands. Our proposal was reviewed anonymously by the relevant stakeholders: researchers, professionals and patient advocates under the auspices of ZonMw. The stakeholders advised us to perform the research among patients with cancer so that the results could be combined with earlier research on this group in the Netherlands. Initially we were not so pleased with this advice, because it forced us to select respondents using Dutch health professionals instead of our own extensive contacts within the Turkish and Moroccan community. It is not acceptable to ask a Turkish or Moroccan patient if his/her illness is cancer. The search for informants via Dutch health professionals took a long time and required great perseverance, as many professionals initially hesitated to allow us to have contact with their patients because they feared that the interview would burden patients and their families. However, the health professionals eventually agreed to introduce me to their patients after they became acquainted with me (a 55+ Dutch woman, who speaks Arabic and a little Turkish) and understood that my intention was not just to interview people, but also to help them communication problems. All families who were contacted to join the research accepted. As a 'side effect' this search for respondents via Dutch health care professionals allowed us to create significant interest in our research topic. These Dutch professionals became supporters of our research in the regional palliative care networks, in hospitals, and health care centres and promised to help us implement our findings at a later stage.

FEEDBACK ON THE RESEARCH PROCESS AND LINES OF THOUGHT

During the research our linking activities aimed at getting feedback from relevant stakeholders during intermediate time periods. We installed an advisory board, comprised of Turkish and Moroccan patient advocates, a physician, a nurse, an oncology specialist, a scientist specializing in palliative care, a Dutch Cancer Foundation policymaker and a home care policymaker. In the first meeting the research proposal was reviewed and discussed. For the second meeting we wrote a preliminary report, although we did not have all the data processed yet. One might think this doubled the work, but we perceived it as a 'try out'. As I had performed all the interviews myself, I had an idea what the early results showed, and I could cautiously write down these ideas. The board members had several comments about the report based on their experiences. Many of them recognized the findings and were pleased that the report included a significant number of respondents' quotations, which brought out the emotional aspect. But some advisors noticed that we did not describe the process of recruiting the respondents; how did we manage to get in contact with so many patients? Other advisors wanted more information about the role of religion and about what the patients and families expected from the physician. As the report focused on miscommunication, the advisors recommended that we include examples of good communication: how misunderstandings can be

prevented or solved, as these examples would encourage practitioners, patients, and managers to address communication problems. Some advices were contradictory. While some advisors could not recognize the difference between the needs of the migrant patients and the needs of religious Dutch patients, others illustrated this difference by highlighting language problems, group values, and the status of migrants in the Dutch society. Some advocated the use of formal interpreters, whereas others disliked this strategy. These discussions helped me as researcher as they demonstrated that some of the identified dilemmas were not going to be solved by the research findings. Therefore based on the outcomes of these meetings we concentrated on issues that could be improved by research.

PREPARING IMPLEMENTATION

The third activity to include policymakers, practitioners, and patients in the research was writing a plan to disseminate and implement the research results. The dissemination process depends on choices in markets and strategies. Implementing requires understanding the minds of potential customers, but one cannot satisfy all stakeholders at once. In order to prepare for timely implementation, ZonMw requires researchers to write an extended implementation plan halfway through their research period. The questions posed by ZonMw compel the researcher to think about the products they want to make, and the way they want to bring their products to the market in consideration of various target groups. Questions to be answered are: • What results do you expect of your research project? • In what environments do you intend to place your results? • What are the opportunities and impediments for future use of your results? • What experiences have you had during your research that are worth mentioning in addition to the project results? • Who are the potential target groups and users of the results? • Which of these groups do you intend to reach by your implementation activities? • What do you know about the size, attainability, interest, and other relevant characteristics of these groups? • What do you want to attain in the field of transfer of knowledge and implementation and why do you want this? You have indicated aims for your research related to the transfer of knowledge and implementation. Is there any reason to change these? • What informing, educating, motivating, or facilitating activities do you plan to use in order to implement your research results? • Who is involved in the planning and the executing of these activities? For the implementation of our research findings we focused on informing and educating professionals and agenda-setting among specialists and advocates of patients with a Turkish or Moroccan background (See Table 2). We asked for feedback on these proposals from the members of the advisory board and they introduced us to key figures in the various target groups, who were eager to help us execute our plans.

[TABLE 2]

TRANSLATING RESEARCH FINDINGS INTO PRACTICAL PRODUCTS

In the last phase of the research we organized several activities to translate the research findings into training materials for health care professionals and patients. Our choice to focus on implementing via educational activities for professionals and Turkish and Moroccan patients' advocates was not only based on the strategic plan for dissemination; it was also influenced by my own professional and personal

background. I have been translating scientific data into professional educational material for many years. It could be that other activities such as lobbying health policy organizations are also needed, but lobbying is not my strongest suit. I can imagine that many researchers will say that translating scientific data into professional educational materials is not their business either. It is not an easy job, so I would suggest that researchers do this in collaboration with educational professionals and with members of their target groups. I still remember how I struggled with the text of a booklet to make it attractive for my readers. I organized reading panels of nurses and physicians to obtain feedback on the text. One of the trainers who coached a reading panel simply reported which pages the readers had been reading and what remarks they had discussed together. I was taken aback to hear that some readers were not interested enough to read the whole text, but it helped me to strive to make the text more attractive. Other readers provided many comments and instructions, what helped me to make the text more accurate. The challenge for this stage of our project was not only to transform scientific texts into practical arguments, written in ordinary language, but also to condense long anthropological stories into brief and clear advice for nurses and medical professionals who have little time to read. Moreover anthropologists and doctors adhere to diverse explanatory models not only in dealing with illness/diseases or care/cure (Kleinman & Van der Geest 2009), but also in working in science and the consequent implications. Anthropologists prefer to use semantic programs, explaining the world of social particulars in patterns, searching for regularities over time and across social space. Sociologists prefer to use syntactic programs, explaining that world by abstractly modelling its particular action and interrelationships. However, medical researchers prefer to use pragmatic programs, explaining the world by separating the effects of various potential interventions or causes from one another (Abbott 2004). Many anthropologists are looking for concepts and stories in order to describe what is socially happening, while a medical professional is looking for solutions to manage what is happening. So although our research results comprise several schemes and many stories, we saw the need to provide tools to enable health professionals to recognize their personal communication patterns, to exercise new communicative methods and to challenge the conditions of their decision-making and problem solving with Turkish and Moroccan patients and family members. Let me give one example how we adjusted our text to make it more palatable and practical for care givers. In the research report (De Graaff, Van Hasselt & Francke 2005) we presented the findings in three different sections: experiences and opinions of relatives (pp. 27-42), of transfer nurses and care-assessors (pp. 45-61), and of general practitioners and home care professionals (pp. 65-78). On the basis of those three sections we formulated our recommendations (pp. 81-84). In the practice-oriented brochure "Tips for terminal home care for Turkish en Moroccan elderly" (De Graaff. & Francke 2002), we incorporated the findings into portraits of two Turkish women and one Moroccan woman who were looking after a terminally sick relative. The three portraits were followed by practical advices under the heading "What can you do for them?". The main 'tips' for professional home care givers were: • Pay attention to all (male and female) family members involved in care-giving; • Learn how to go about certain rituals and cultural taboos that were observed during the research; • Inform the family members about the different possibilities of professional care at home.

Workshops and trainings are important aids in developing tools to implement our research findings. I had the opportunity to give presentations or trainings in several refresher courses for nurses and medical professionals and in lectures at several universities. Each workshop or training helped us to determine the benefits of our research for this particular group of professionals and how we should present data to them in an appropriate manner. Carers, nurses, general practitioners and specialists need different approaches and different material, because their learning styles are different. In our experience, carers prefer practical exercises, while specialists prefer reading (short) articles. Carers are eager to meet each other and discuss their experiences in several training sessions, physicians ask for short presentations. So in collaboration with a teacher in nursing I developed and executed a five sessions training for nurses (De Graaff & Bertens 2008). The curriculum included the following: • examining one's personal background and the cultural aspects of family life, • theory and practice of intercultural communication, • examples of transcultural nursing, • exercises on the use of personal interpreters and translations via a telephone, • interviewing a non-Dutch patient about care-related topics, • discussing special needs of migrant patients and their families comparing them with the needs of Dutch patients, now and in the past. For physicians we developed workshops presenting the most important findings of our research (see Table 1), but these were not expected to influence their professional routines structurally. To influence physicians' formal procedures, such as existing national guidelines on palliative care, the culture-specific needs of migrant groups should be taken into account. We wrote a separate project plan to study how some national guidelines could be supplemented with advice on how to apply the guidelines in a culturally sensitive way. This proposal was submitted by NIVEL (The Dutch Institute for Health Services Research) in cooperation with University of Amsterdam and Pharos (Knowledge and Advisory Centre on Refugees, Migrants and Health) and funded by ZonMw. Finally we planned and executed implementation activities for patients, their relatives and advocates. We developed audiovisual material demonstrating the main results of the research and organized meetings to discuss these films with groups of interested Turkish and Moroccan women and men. The material and results of these meetings will be translated in several languages and further disseminated by Internet sites such as www.mammarosa.nl.

SHOULD COMBINING THE ROLES OF RESEARCHER AND CHANGE-AGENT BE RECOMMENDED?

A researcher who wants to perform research that can be used in practice must recognize that it is essential to share the objectives of the research with the intended end users. In addition, it is critical to conduct robust research and clearly communicate the results with all stakeholders. Acting as a change-agent is a further step. Researchers who dare to take this step have to realize that community-based research requires a different problem-structuring process than does traditional mainstream research. Collaboration with various stakeholders requires that the researcher consciously fulfils his/her various roles: • As a facilitator for the stakeholders without becoming too involved or reaping the stakeholders' 'harvest'; • Connecting with funding organizations without uncritically following their aims, • Bringing insights about structures and processes to managers, professionals and patients while acknowledging that the innovation-diffusion process will not catch the

attention of the majority all at once (Bodorkos & Pataki 2007; De Caluwé & Vermaak 2003; Grol et al. 2007). One should recognize that action research cannot replace other forms of health research. After all, some research questions need answers on a level that is beyond that of the direct users. Another example is research findings that should be verified in other settings to evaluate their validity and reliability under different conditions. But involvement in the implementation and reflection on these activities can be useful as it highlights the practical issues facing individuals when they attempt to implement policy on the ground (Huxham 2003). Researchers might prepare themselves to the question how to make their findings useful for the people concerned. Because, although they should not be fully responsible for the link between their research and policymakers, practitioners and patients, the researcher's new insights and emotional involvement with their results could be valuable for policymakers' agendas or solving a matter in practice. By reflecting on their interventions researchers can contribute to the growing body of knowledge about the possible ways to bridge the know-do gap (Haines et al. 2004).

CONCLUSIONS

Practice-oriented anthropological research and policymaking/healthcare are entangled in a cyclical process. In order to do useful research, policy questions and practical questions have to be translated into research questions and research findings have to be translated into advice that can be used in practice. Some researchers concentrate on doing research leaving out these critical elements and allow others to do the followup. That is their choice. But some also prefer to be – at least partly – responsible for the connection between theory and practice. This takes time, dedication, special skills and network contacts. When one is dedicated, one can develop these skills and contacts. This case study might contribute to the joining of forces in linking health research to policy makers, practitioners and patients.

Note

Fuusje de Graaff is a social scientist and partner in the consultancy and training organisation MUTANT, in the Netherlands. She is specialized in intercultural communication in health care and has written several books on this subject for nurses, midwives and general practitioners, teachers and childcare workers. Through her involvement in training programs and research she is working to improve intercultural understanding and acceptance in society, so that particularly the young, the sick and the elderly can live in an environment of respect. Email: fuusdegraaff@wxs.nl The research discussed in this paper was funded by ZonMw, a Dutch organisation for health research and development in the Netherlands that promotes quality and innovation in the field of health research and health care, initiating and fostering new developments. Fuusje de Graaff conducted the research, supervised by Professor Anneke L Francke (NIVEL and VUmc/ EMGO). In this article the pronoun 'we' is used for their common activities, while 'I' is used for specific contributions by the author.

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TABLES

Tabel 1 Conflicting views on 'good palliative care'

<i>Dutch care professionals' principles</i>	<i>Moroccan / Turkish patients' principles</i>
<i>Information to facilitate the patients' decision making</i>	<i>Hope breeds life, patient does not need full information</i>
<i>Advanced care planning</i>	<i>Allah decides, live from day to day,</i>
<i>Weighing pros and cons to attain optimal quality of life</i>	<i>Maximal care, seen by community</i>
<i>The patient is the responsible communication partner</i>	<i>The family is the responsible communication partner</i>
<i>No discrimination on sex in professional care supply</i>	<i>Care by same sex, women prefer care by female carers, man are generally cared for by women</i>
<i>Accustomed to naked bodies and blunt behaviour</i>	<i>Alert to chastity and shame</i>
<i>Programmed care, patients should rest</i>	<i>Continuous care, patients should eat, move, be accompanied and surrounded by believers</i>
<i>Dying comfortably thanks to pain reducing measures</i>	<i>Dying with a lucid mind for the encounter with Allah so little use of pain reducing measures</i>

Table 2 Implementation of tools to improve communication and decision-making in inter-cultural palliative care

<i>Target groups</i> →	<i>Nurses</i>	<i>General practitioners</i>	<i>Specialists</i>	<i>Moroccan and Turkish patients and their advocates</i>
Acquainted with the subject?	Yes	Yes	Yes	Yes
Interested to learn about the subject?	Yes	Yes	No	Yes
Active in organizing training about the subject?	Yes	No	No	No
Intended communication strategy	Developing an educational module for dissemination in a 'Train the trainers' format.	Developing an educational module and organizing workshops within existing training programs.	Agenda-setting by informing palliative networks	Developing audiovisual material and organizing discussions with Moroccan and Turkish patients, their relatives and advocates supported by this material