

# The stepwise development of a comprehensive family caregiver support programme

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## **CHAPTER 8**

### **Summary**

In Germany and internationally, the complex needs of (stroke) family caregivers are often insufficiently addressed due to fragmented, unsuitable, invisible, delayed or even missing support offers within the existing support system. Moreover, during transferal and discharge of the patient, caregivers frequently experience inadequate involvement and lack of preparation for their new role by the system. It is worth mentioning that family caregivers are the key contributor of the long-term support in the home environment, as they provide individual care, emotional support and health navigation assistance to the patient voluntarily (adapted from Family Caregiver Alliance 2018).

Right from the beginning of the patient's hospitalisation phase, caregivers have complex support needs which continue to change during the patient's rehabilitation trajectory. Caregivers may require informational, emotional, psychological and/or peer support. Therefore, insufficiently addressing caregiver's needs may pose negative consequences on their physical, psychological and social health and may reduce the quality of life substantially.

From the public health point of view it is important to invest in the careful development, implementation and evaluation of comprehensive caregiver interventions, in a way to respond to the complex needs of both the individual end-users of the intervention, f.i. family caregivers, and the needs of the system's service providers, f.i. health professionals. Complex interventions which contain different components and involve multiple stakeholders are most promising.

A personalized and long-term stroke-caregiver support programme, starting early in the acute phase, is missing in Germany. In the Aachen region (Germany), an innovative, multicomponent primary prevention programme for stroke family caregivers - the Caregivers' Guide - was initiated in 2012 and was continuously developed, implemented and evaluated until 2015. Its purpose was to maintain stroke caregivers' quality of life and to reduce their burden by offering professional support parallel to the existent patient-centred stroke rehabilitation trajectory. In Chapters 2, 3, 4 and 5 of the dissertation a detailed report is given on: (1) how the Caregivers' Guide was developed and implemented; and (2) what the perceived outcomes of the intervention on both the individual and the societal levels were.

After completing the Caregivers' Guide, a new programme for family caregivers in the geriatric setting, so-called Vade Mecum, evolved as a spin-off (2017). Here, we completed the project life cycle of the initial caregiver intervention with this new project initiation phase in a large geriatric hospital setting in Aachen. It was initiated by applying the participatory health research (PHR)

strategy, which was innovative for the public health domain. The purpose of this new study was to: (1) assess the existing caregiver support offers provided by the multidisciplinary team, and (2) explore professionals' needs for providing comprehensive caregiver support.

The development phase in the lifecycle of the Caregivers' Guide included two steps: (1) developing the preliminary concept which resulted in five 'Conceptual Building Blocks' (CBB), and (2) designing of implementation management instruments.

Chapter 2 describes the development of the Caregivers' Guide where we applied a naturalistic inquiry approach. A qualitative mixed-methods design was used for data collection. First, three separate, explorative, inductive, qualitative sub-studies were conducted: (1) seven explorative interviews with experienced stroke caregivers, (2) six semi-structured interviews with professionals working within stroke rehabilitation, and (3) seventeen participant observations with focus on professional – caregiver interactions. Regional stroke units, rehabilitation centres, outpatient services, and the home care providers were included. By means of a four-step qualitative content analysis, all three datasets were coded, categorized and subsequently condensed into subthemes. Second, outcomes were merged in one overarching qualitative study, clustered into main themes, and finally translated into preliminary CBBs. In all three sub-studies the need for a personalized, holistic and multicomponent caregiver support intervention emerged. The newly developed concept consisted of five flexible CBBs: 'Content', 'Human Resources', 'Personalized Approach', 'Timing', and 'Setting'. The CBB's development was based on the actual contextual needs of stroke caregivers within the existing support system. The application of mixed-methods helped to comprehend the complexity from different perspectives and enabled the context-tailored development the preliminary concept with its CBB's.

Chapter 3 concentrates on the second step of the development phase, the design of instruments, aimed to facilitate the implementation of the complex stroke caregiver intervention in the real-life support system. First, different project management techniques were used to systematically analyse the projects' stakeholders and possible implementation risks. Stakeholders were identified, classified and assessed using a top-down approach, while implementation risks were identified and assessed applying a bottom-up approach. Second, stakeholders and risks specific knowledge was applied to develop context-tailored

implementation management instruments. This top-down process resulted in developing two instruments: (1) a comprehensive `stakeholder-risk atlas´ providing individual stakeholder information, and (2) an overall `project implementation strategy´. Systematic analyses enabled the research team to develop context-tailored implementation management instruments. Through stakeholder involvement and engagement insightful system knowledge was generated. Implementation management instruments can facilitate the implementation process and may positively impact the intervention´s outcome.

Chapter 4 illuminates the conceptual optimisation process of the Caregivers´ Guide preliminary concept with its five CBB´s when implementing in practice. Optimisation comprised three steps: (1) verifying and fitting the five preliminary CBBs, (2) detecting, developing, verifying and fitting new blocks, and (3) prioritizing all blocks. Participatory Action Research (PAR) which includes iterative cycles of four phases: observe, reflect, plan and act, was applied. A multi-methodological design was chosen to collect data. Optimisation resulted in the Caregivers´ Guide matured concept, containing eight CBBs. The five preliminary CBBs: `Content´, `Human resources´, `Personalised approach´, `Timing´, and `Setting´, were improved and prioritised to be the core blocks, providing the base for individual caregiver support. The three new building blocks: `Network building´, `Communication´, and `Social safety-net´ were selected to serve as facilitating blocks, safeguarding the intervention within the complex everyday working routine in the support system. PAR helped to early detect conceptual weaknesses, adapt the concept to the actual needs of both the end-users and the system, and improve the programme´s feasibility. Hereby, stakeholders´ participation was crucial and their early engagement enhanced the interventions´ acceptance in the system. Optimisation may improve the interventions´ effectiveness.

Chapter 5 describes the evaluation of Caregivers´ Guide intervention. We aimed to gain a comprehensive understanding of the interventions´ impact on both individual and system levels. A multi-methodological approach was applied for data collection. Two interconnected studies with two groups of participants were conducted: (1) new caregivers participated in a pre-post design with a quantitative questionnaire and a post-intervention qualitative design with a semistructured interview (quant-QUAL), here they reflected on their individual experience with the intervention as end-user (individual level); and (2) stroke care professionals from different parts of the support system participated

ex-post with an interview (QUAL-QUAL), reflecting on the impact of the intervention on the supported end-users (individual level) and on their perceived impact on the current stroke support system (system level). Quantitative data showed that providing personalized information improved caregivers' health literacy significantly, and offering psychosocial support stabilized caregivers' psychosocial health. Qualitative data clarified health literacy enhancements regarding knowledge, capability to act and individual empowerment, and psychosocial stabilisation of self-confidence, life balance and emotional well-being. The professionals (system perspective) stated that communication and network-building helped improving the system by positively influencing the daily work, institutional support, quality of care and inter-institutional cooperation. A comprehensive understanding of the interventions' impact was achieved on both levels.

Chapter 6 describes the initial step of the project cycle of assessing the actual situation of the caregiver support provided by the multidisciplinary team in one geriatric department in the Aachen region, and the exploration of professionals' needs for providing comprehensive caregiver support. Participatory Health Research (PHR) strategy was applied in a qualitative study design.

Multiprofessional members from the department were engaged as co-researchers. By the facilitation of an external impulse provider (professional researcher – PhD applicant), a research team was formed and its members were enabled to develop the research question, choose appropriate data collection methods, develop data collection instruments and decide on suitable procedures of engaging family caregivers. Needs and expectations towards the new concept were discussed and research objectives were formulated. A suitable mix of qualitative data collection methods consisting of interviews, focus groups and story-telling, was chosen. Practical solutions for involving family caregivers were discussed. PHR strategy resulted in initiating a qualitative study in the geriatric care setting carried out by their own professionals. High levels of participation were achieved. Knowledge was generated in a co-creative manner, and co-researchers were empowered. Comprehensive understanding and insightful knowledge of the system serves as a starting point for developing a context-tailored new family caregiver concept.

Chapter 7 provides a summary of the main outcomes and a reflection of the entire study as well as some methodological considerations and implications for future research.

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