

The stepwise development of a comprehensive family caregiver support programme

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Valorisation

This thesis focuses on the stepwise development of a comprehensive caregiver support programme, which was conducted in Aachen, Germany. The current work provides new insights concerning the requirements for a holistic support programme. Parallel to the prevailing patient-centred support system, a system-centred support offer for family caregivers was developed.

The new programme, the Caregivers' Guide, operates on two levels: on the individual family caregiver level as well as on the support system level, which were interconnected with each other from the start of its development. On the individual level, a specially trained social worker offers personalized information and psychosocial support to family caregivers. On the system level, the new programme is interlinked with the existing care and support system by organising activities that enhance network-building and communication between the different support providers, e.g. in workshops, and provide social safety-net opportunities for the involved family caregivers after discharge.

Furthermore, Vade Mecum, a new programme to support family caregivers of elderly in the geriatric department in Würselen, was initiated. A multiperspective understanding of the needs on the individual caregiver and the system level was achieved.

This chapter highlights how the results of this thesis could be beneficial for those who contributed as key stakeholders. In addition, it highlights how the study could contribute on societal level and to the field of public health.

This study aimed to enhance the societal impact by creating value from knowledge by making it suitable and available for societal use as well as translating that knowledge into services (adapted from Drooge & Jong, 2016). Both the programme's end-users, being the family caregivers, as well as the organisations and their individual practitioners, being the service providers within the system, were involved in the new programme's development process. From the start, the whole study was valorised with the participation of both groups of key stakeholders. Productive interactions, collaboration with knowledge users as well as involvement of knowledge users led to new, context-specific and practice-based knowledge. This was subsequently translated into the final product: a holistic caregiver support programme. During the programme's life cycle, members of the broader society and the research team also valued the collaboration and productive interactions.

Family caregivers

In Germany, the offer of a holistic caregiver support programme like the Caregivers' Guide would be of great value for family caregivers as it will assist them in preparing for and coping with their new role.

Offering needs-driven and personalized information and psychosocial support as focal part of the holistic programme resulted in improving caregivers' health literacy and helped to (re)-stabilize caregivers' psychosocial health as well as safeguard continuity of support within the system.

For being holistic, a programme needs to consider not only the 'content', e.g. informational and psychosocial support. Other elements turned out to be crucial for the programme's success. During its development and pre-implementation phase, we illustrated that it is possible to develop such a complex programme within an existing care system, with the following elements: early start and for as long as needed (timing), outreach counselling, personalized support mode, professional support, and own choice of place where the counselling is offered (Chapter 2 & 4). We also specified that all these elements need to be interconnected in a flexible manner.

Our results underline the importance of offering one holistic and flexible support programme developed with the participation of both key stakeholders: end-users and service providers. Their contribution was imperative for gaining a multiperspective understanding and for achieving conceptual maturity, feasibility and acceptance in practice. The service providers contributed in the development of the two management instruments, which aim to guide implementation on programme level and to facilitate the day-to-day interactions with the stakeholders (Chapter 3).

Throughout the entire project life cycle, caregivers were valued by having direct contact with the research team and giving them a voice. Productive interactions between the caregivers and the research team helped to exchange information and experiences, which contributed in gaining a comprehensive understanding of the complex caregiver needs. The appreciation of caregivers' knowledge and the consideration of their expectations shaped the programme from the start of the first contacts with experienced caregivers. During the optimisation phase, family caregivers contributed by critically reflecting on their experiences with

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the new support offer. Their input assisted the team in tailoring the programme to caregivers' actual needs.

The need for early and long-term support along the stroke care trajectory was addressed by the new programme, which was much valued by both the family caregivers and the service providers (Chapter 2 & 4). Existing support offers in the geographic region Aachen are fragmented and do not proactively engage with family caregivers. However, services, e.g. Kommunaler Pflegestützpunkt, state that most caregivers ask for support too late. Applying an outreach counselling strategy was considered as very valuable by both family caregivers and service providers (chapter 4).

Opposed to common counselling offers in organisational settings, e.g. in the hospital, the opportunity to obtain counselling in a safe environment, e.g. at the caregivers' home, was much appreciated by the programme's end-users. Caregivers specified that this element was especially important in the beginning, when they felt destabilized, e.g. emotionally (chapter 4).

The new programme is interconnected with the actual support system. For that reason, caregivers and professionals within the support system were encouraged by the programme to interact with each other on an individual case level, e.g. during transfers. The knowledge transfer in two directions was valued by both end-users and system providers. It helped to reduce the communication gaps and weaknesses caused by the fragmented support trajectory and helped to understand and address the needs of both caregivers and service providers during transitions.

The programme's internal and external communication activities, e.g. website and press releases, and network-building activities, e.g. participation in the caregiver symposium, were valued by both caregivers and service providers. On the one hand, the multiple direct and indirect interactions were time-consuming. On the other hand, both activities were perceived as crucial to arouse attention within the society, to facilitate early programme access for caregivers and to interconnect the programme with other support offers within the region, e.g. with practical caregiving courses for the health insurance providers.

The new programme valued caregivers' desire for interacting with peers. We facilitated the establishment of a stroke caregivers-specific peer group within the

region. Engagement with this group was proactively offered to caregivers in the end of each counselling trajectory. This opportunity was much valued by the caregivers.

The caregiver-focussed programme offers flexible and personalized support by considering different caregiver groups, e.g. spouses, adult children. Moreover, it addresses the various support needs, e.g. emotional support or informational support (Chapter 4). Although this is speculation, our programme might also have had a beneficial effect on the patient. Service providers contemplated that the holistic support might prevent rehospitalisation of the care receiver by equipping the caregiver better for the new role, e.g. with knowledge and skills. However, our way of developing the programme was aiming to address the needs of the caregiver and not of the patient.

Practitioners

From the start and throughout the entire project life cycle, this holistic caregiver support programme was highly valued by the multiprofessional practitioners, being the service providers within the fragmented support system.

The added support for family caregivers by a professional counsellor was perceived as positively impacting on practitioners' professional performance, the institutional support, the interinstitutional cooperation, the quality of patient care, and the health system development.

The new programme was developed with the participation of practitioners with different professional backgrounds working in the acute, rehabilitation and home care support. These efforts led to a multiperspective understanding of the needs of both the caregiver and the system. Professionals' knowledge and extensive experiences were valued in productive interactions, e.g. weekly reflections within the case managers and social workers in the acute care hospitals. Professionals contributed in the participatory transdisciplinary research during PAR (Chapter 4). Based on their input, three facilitating blocks were added to the core blocks, addressing the system needs: network building, communication and social safety-net.

The new programme sensitized practitioners within the multidisciplinary support team regarding the complexity of caregiver needs and helped to develop a

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‘pro-caregiver’ climate within their setting. As consequence, caregivers were more and more included in transferal or discharge activities, which was valued by the professionals as securing the quality of care of the patient in the home environment. The ‘caregiver-specific information box’, which was developed by the programme, may be further utilized by the professionals, e.g. by social workers (Chapter 4). The different documents, written in ‘caregiver-friendly’ language, may assist caregivers in recalling the information given in the personalized counselling session.

High participation modes (Cornwall, 1996) were achieved in the Caregivers’ Guides optimisation and Vade Mecum’s initiation phase. In both settings and opposed to the common resistance to modifications, our investments, e.g. in time and resources, resulted in triggering change within the system on individual, professional and system level (Chapter 5 & Chapter 6). Participation was valued by the professionals as it was perceived by improving their professional performance, e.g. improved collaboration with other service providers.

The programme enabled interprofessional exchange and interinstitutional collaboration. It fostered the process of developing a professional caregiver-focused network within the region. These long-term professional relationships caused synergy effects between the different service providers, e.g. facilitating early contacts between acute clinics and communal services, so called “kurzer Dienstweg” interactions, which was valued as most effective by some professionals. They specified that this interprofessional network augmented their intrinsic working motivation, as especially in difficult cases practical solutions were found in a co-creative manner (Chapter 5).

Professionals in the acute and rehabilitation support system welcomed the option of counselling in the caregiver’s home for more practical, patient-centred reasons. Professionals in these settings are currently not allowed to conduct home visits. Therefore, the opportunity to professionally assess the feasibility of home caregiving and the specific needs was considered as safeguarding the quality of care of the patient after transferal (Chapter 5).

Today in Germany, the dynamic and economically driven changes within the health and support system require the further development of the health system, e.g. creation of new job profiles. In the course of the Caregivers’ Guide life cycle, the requirements for a special caregiver counsellor were developed in a

co-creative manner and tested for its feasibility (Chapter 2, Chapter 4). This job description, specifying tasks, competences, experiences, social skills and personality traits, may be useful for professionals in management positions.

Societal level

During the second part of the Caregivers' Guide funding phase, more than a few valorisation strategies were applied on societal level. The communal decision makers and the governmental health insurance providers were valued by providing information regarding the programme and its outcomes. In different productive interactions we exchanged caregiver specific information and augmented the consciousness for the complex and long-term needs of family caregivers. The role of the governmental health insurance providers and the communal social services was taken into account by exploring the scope for the programme's transferal into the current support system on regional and communal level in a collaborative manner.

We applied also indirect interactions for valorisation. On federal level, we contributed an "advisory transdisciplinary research" activity, which was aimed at supporting political decision makers in their attempt to improve caregivers' role and to offer appropriate support. This work, together with the other academic contributions, was much appreciated by the commissioner (MGEPA-NRW, Ministry for Health, Emancipation, Nursing and Ageing in North Rhine-Westphalia).

Scientific community

Apart from generating new and context-specific knowledge regarding family caregiver support in Germany, our study is, to our knowledge, the first published study addressing the complex needs of caregiver support on two interconnected levels, both on individual as well as system level, in one holistic support programme. The approach may set impulses for further research in the field of public health. It may stimulated knowledge users, e.g. researchers or health system developers, to consider the complexity of such programmes in terms of the required components, staff, resources or research resigns.

Our study showed that applying methodological pluralism and investing in including both end-users and service providers resulted in gaining a multiperspective understanding of the actual situation and the needs. This comprehensive approach may assist complex intervention planners and researchers during the initiation, development, implementation and evaluation of a new programme.

During the programme, the efforts made to achieve high participation levels (Cornwall, 1996) resulted in overcoming the gap between theory and practice. Consulting the programme's key stakeholders, cooperating with the professionals and asking for their active voice (mode 4) lead to achieving a co-learning atmosphere (mode 4), which was very supportive for the new programme. In Germany, participation modes beyond consultation are still seldom in the field of public health. Public health approaches can be potentially valorised, when high participation levels were achieved during their development.

In our study, applying the Participative Health Research (PHR) strategy resulted in an in-depth understanding of the complex needs of both the caregivers and the system (Chapter 6). The study's outcomes may motivate other colleagues to invest in early stakeholder engagement and apply different participation strategies during the project's life cycle. This practice-based knowledge may assist researchers and planners in the challenging task of the development of a needs-driven, feasible and acceptable new public health programme.

Transdisciplinary knowledge was applied in both studies. Techniques and strategies from the project management, e.g. stakeholder and risk analyses, as well as from systems- and design thinking, were introduced in a public health programme (Chapter 2, 3 & 6). It was considered as helpful for the development of this holistic caregiver support programme. Public health researchers may benefit from these techniques and strategies in all phases of a programme.

During the study, dissemination efforts resulted in direct and indirect productive interactions. The new knowledge was disseminated within the scientific community by publishing in international, peer-reviewed journals, contributing on the debates in international conferences as well as by enabling web-based discussions, e.g. via research gate. Likewise, knowledge was directly distributed also to practitioners within the system. Two interprofessional capacity building workshops, focussing on caregiver needs, and two methodological workshops, regarding the Participatory Health Research strategy, were conducted. Both direct and indirect interactions may provoke constructive feedback, which supplements to researchers' knowledge base and contributes in empowering the researcher professionally and individually.