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Two-level multi-methodological evaluation of a new complex primary support programme for stroke care-givers in Germany

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(Accepted 13 May 2020; first published online 10 June 2020)

Abstract

Family care-givers are the backbone of the long-term support system for care receivers at home. Care for stroke survivors after rehabilitation primarily rests on the shoulders of family members, often of older age themselves. We report the outcomes of a new complex support programme, the Care-givers' Guide, on both individual and system levels. Psycho-social support and personalised information were the main ingredients of this intervention. A two-level multi-methodological approach was needed, with two concurrent interconnected studies. Family care-givers reflected on outcomes at an individual level in a quant-QUAL study with a pre–post quantitative questionnaire and a post-intervention qualitative semi-structured interview. Practitioners participated in a QUAL-QUAL study *ex post* interview, reflecting on the outcomes on the care-givers and on their own stroke care system. Individual family care-givers showed an increase in health literacy and level of psycho-social health. Qualitative analysis revealed improvement in knowledge, capability to act and individual empowerment; and stabilisation of sense of certainty, life balance and emotional wellbeing. Practitioners observed an optimisation of the stroke support system by improving professionals' daily routine, augmenting the institutional support offer, securing the quality of patient care and increasing inter-institutional co-operation attempts. Positive outcomes of the support programme were observed on both evaluation levels: family care-givers showed improved health literacy and psycho-social health, whereas the professionals noticed an optimisation of the support system.

Keywords: family care-giver; complex intervention; stroke; mixed methods; evaluation; individual and system level

Introduction

Stroke is the primary cause of disability worldwide (Thrift *et al.*, 2014), especially in the elderly (Johnston *et al.*, 2009; Kelly-Hayes, 2010). After rehabilitation, stroke survivors have to cope with substantial physical, cognitive and emotional deficits

(Bonita *et al.*, 2004). In their everyday life at home they usually need care and assistance from family members (Bakas *et al.*, 2014). Family care-givers are relatives, partners, friends or neighbours, who provide voluntary physical, practical and emotional care and/or support to a person with a chronic disability in the home environment (Candy *et al.*, 2011; Family Caregiver Alliance, 2019). Most family care-givers caring for an elderly patient are also over 65 years of age, and are likely to suffer from declining health themselves (Camak, 2015; Family Caregiver Alliance, 2019).

Compared with other care-giving situations, such as in Alzheimer's dementia, the suddenness of a stroke, with an abrupt onset of complex demands, is challenging for the family (Redfern *et al.*, 2006; Legg *et al.*, 2011). Family care-givers can feel pressurised by the expectation from professionals in the system that they are able to manage immediately individual, interpersonal and organisational issues, without enough time to adjust to the new situation or to find their way within the support system (Murray *et al.*, 2003; Grant *et al.*, 2014). New care-givers, in particular, may suffer from low health literacy concerning the consequences of a stroke, but may also be unfamiliar with the stroke support system in their setting, or lack the knowledge and skills to master care at home (Smith *et al.*, 2004). Complex demands of care-giving may influence negatively the family care-giver's own physical, psychological, psycho-social, social health or financial situation (Lutz and Young, 2010; Adelman *et al.*, 2014). Many long-term stroke care-givers suffer from depression (Han and Haley, 1999) and social isolation (Tooth *et al.*, 2005).

The professionals in the health-care system often ignore the needs of stroke family care-givers (Sanders *et al.*, 2014; Chen *et al.*, 2015). Family care-givers require informational, emotional, psychological, psycho-social and peer support (Wilz and Böhm, 2007; Li *et al.*, 2017), as well as coaching during patient's transitions (Egan *et al.*, 2010). The provision of psychological first aid seems to be essential (Gunderson *et al.*, 2012). Family care-givers can feel marginalised or overlooked by support services, may lack sufficient communication with professionals, or may have limited awareness of services and involvement during transfers of the patient (Ng, 2009; Chen *et al.*, 2015; Pindus *et al.*, 2018). Insufficient preparation to cope with the stroke survivor's impairment after hospital discharge can foster complications, leading to rehospitalisation, the so-called 'revolving door' phenomenon (Perry and Middleton, 2011; Carlson *et al.*, 2012).

Over the last decades, numerous stroke care-giver support programmes have been developed and tested (Bakas *et al.*, 2017). Overall, stroke care-giver support initiatives vary in content from specialist services, (psycho-)education, counselling and social support by peers (Visser-Meilly *et al.*, 2005). Most interventions are multi-component, including information provision, education and counselling (Smith *et al.*, 2012; Ostwald *et al.*, 2013). Interventions also vary in approach, *e.g.* personalised or group support, number of sessions or actual support time, from *e.g.* a two-hour session (Aguirrezabal *et al.*, 2013) to a 12-week support service (King *et al.*, 2012). No programme operating parallel to the whole stroke patient care pathway could be found in the literature, but there were examples of care-giver support programmes in specific phases in the stroke patients care trajectory. For instance, Forster *et al.* (2013) offered a structured care-giver training programme in the acute stroke phase in hospital, whereas Aguirrezabal *et al.* (2013) offered their programme in the rehabilitation phase, and Ostwald *et al.* (2013) in the

home care phase. In the majority of the interventions reviewed recently by Bakas *et al.* (2014), the effect of the support programmes was measured and evaluated only at individual care-giver level. A multitude of evaluation instruments was used, showing changes on care-giver's preparedness, knowledge, anxiety and depression, burden, strain, quality of life, social functioning, service use and satisfaction with the support were measured (Bakas *et al.*, 2014). Greenhalgh *et al.* (2016) emphasised the importance of the system, but no reports on the impact on the support system itself were found. Nevertheless, building up a professional support network, discovering new support offers and optimising the quality of care for the stroke survivor are thought to be paramount for the care-giver (Visser-Meilly *et al.*, 2005).

Family care-giver support in the German stroke care system

In Germany, the entire stroke rehabilitation process is fragmented (see Figure 1). It is characterised by multiple transition points and diverse bureaucratic, informational and logistical bottlenecks (Schuler and Oster, 2004). The system lacks co-ordination, communication and navigation through the different phases and affiliated services on individual and societal levels.

Regional stroke units apply predominantly a patient-centred approach. Most of these units have implemented a case management system in order to facilitate a smooth patient transferal process from acute to rehabilitation care, but still fail to actively invite family care-givers to participate in these transferals (Küttel *et al.*, 2015). Even the good practice project of the German Stroke Association, 'Schlaganfall-Lotse', puts attention only on the patient and not on the care-giver-patient dyad (Manteufel, 2012). In general, one-size-fits-all care-giver support is offered, haphazardly, for instance by health insurances (Gesetzliche Krankenversicherung (GKV), 2011; Allgemeine Ortskrankenkasse, 2019) or communal services. Moreover, most of these services, even the well-known 'Familiale Pflege' project, focus on the improvement of 'nursing' skills, without taking the care-giver's own needs into account (Gröning *et al.*, 2018). In Germany, a comprehensive, nation-wide care-giving policy is missing (GKV, 2011), and a holistic stroke care-giver support programme that supports care-givers' informational and psycho-social needs across their trajectory was not available.

The Care-givers' Guide programme

The Care-givers' Guide is a new primary prevention programme that was recently initiated, developed and implemented by the multi-disciplinary team of the Institute for Health Research and Social Psychiatry (igsp) in the Catholic University of Applied Sciences North Rhine-Westphalia in Aachen, Germany (2012–2015). The overall objective is to provide professional needs- and process-oriented support to stroke family care-givers (Jungbauer *et al.*, 2014). Care-givers are to be approached via outreach counselling and supported throughout the entire stroke care trajectory by a specially trained counsellor (clinical social worker), from as early as possible after stroke and for as long as needed and with as many sessions as necessary.

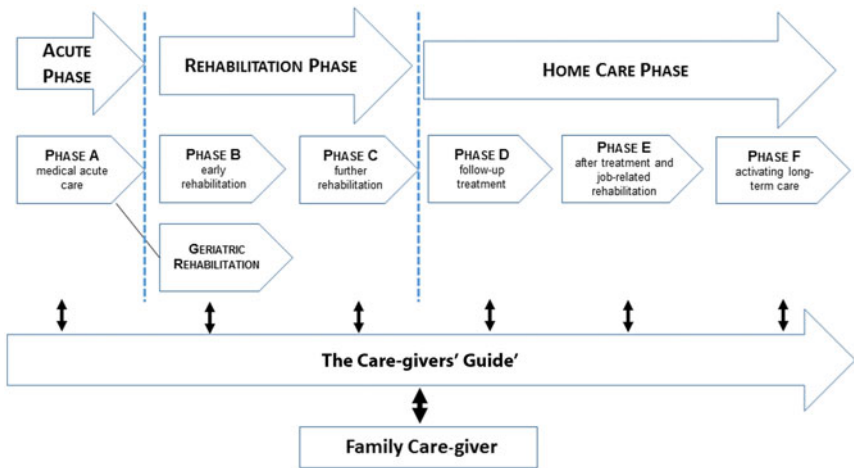


Figure 1. The German stroke rehabilitation support system and the timing of support by the Care-givers' Guide.

Source: Adapted from Bundesarbeitsgemeinschaft Rehabilitation (2014).

The actual Care-givers' Guide programme consists of eight conceptual building blocks (CBB) (Krieger *et al.*, 2019). Five core blocks, 'Content', 'Human resources', 'Personalised approach', 'Timing' and 'Setting', essential for personalised care-giver support, were developed in the programme's development phase using insider knowledge from important stakeholders revealed through qualitative research methods (Krieger *et al.*, 2017). The three facilitating blocks, 'Network building', 'Communication' and 'Social safety-net', that together will serve as a lifebelt for the programme within the existing support system, were developed in the programme's optimisation phase, before the programme was implemented, by using Participatory Action Research (Krieger *et al.*, 2019). To manage the implementation of the programme, two instruments were developed using the inputs of a combined stakeholder and risk analysis (Krieger *et al.*, 2020). A regional care-giver peer group had to be established by the project group to fill a gap in the desired support offer.

The complete programme with its eight CBBs, as well as each individual CBB, was set up to be flexible, in order to address variations between individual care-givers and system needs, also over time as new situations might emerge (Figure 2).

In this article, we report on the evaluation of the Care-givers' Guide on two levels. Outcomes on the individual stroke family care-giver and the perceived benefits for the stroke care system are described.

Methods

In accordance with the Medical Research Council guidelines, this multi-component programme has to be considered and therefore evaluated as a complex intervention (Craig *et al.*, 2008). To address its complexity, a two-level multi-methodological approach was necessary (Creswell *et al.*, 2004; Morse and Cheek, 2014), with two

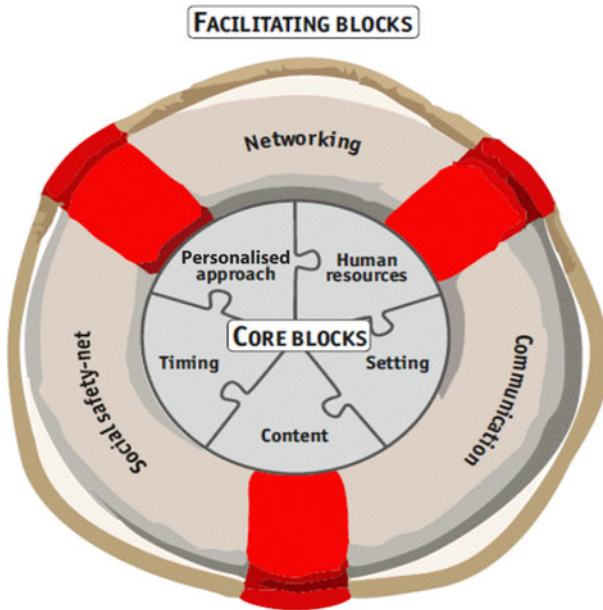


Figure 2. The conceptual building blocks of the Care-givers' Guide on individual and system levels.

concurrent interconnected parts (see Figure 3) and an explanatory sequential design (Ivankova *et al.*, 2006).

Participants

Group 1: stroke family care-givers

Participants were first-time family care-givers with a prospective role as care-giver of a stroke patient, who lived in the region of Aachen. All participants had to be referred to the programme by professionals (not earlier than three days post-stroke) after entering the acute stroke care unit with their patient. Expectations on the prognosis of the stroke should allow for a favourable prediction on return to home.

During the admission period, 76 new stroke family care-givers were referred. However, 14 care-givers dropped out due to worsening of the patients' situation or death ($N = 7$) or for reasons related to the care-giver, such as low compliance or unstable health status ($N = 7$).

All care-givers that completed both pre-intervention (T0) and post-intervention (T1) questionnaires ($N = 62$) were included in the quant-QUAL (quantitative-qualitative) (Figure 3).

Each care-giver received tailor-made counselling support from the programme's counsellor for as long as needed. The place of counselling (usually in the home), length (varying from five to nine months) and content (*e.g.* information provision) could be fitted to the needs of the care-giver.

On average, the support period between T0 and T1 lasted six months and contained six counselling sessions.

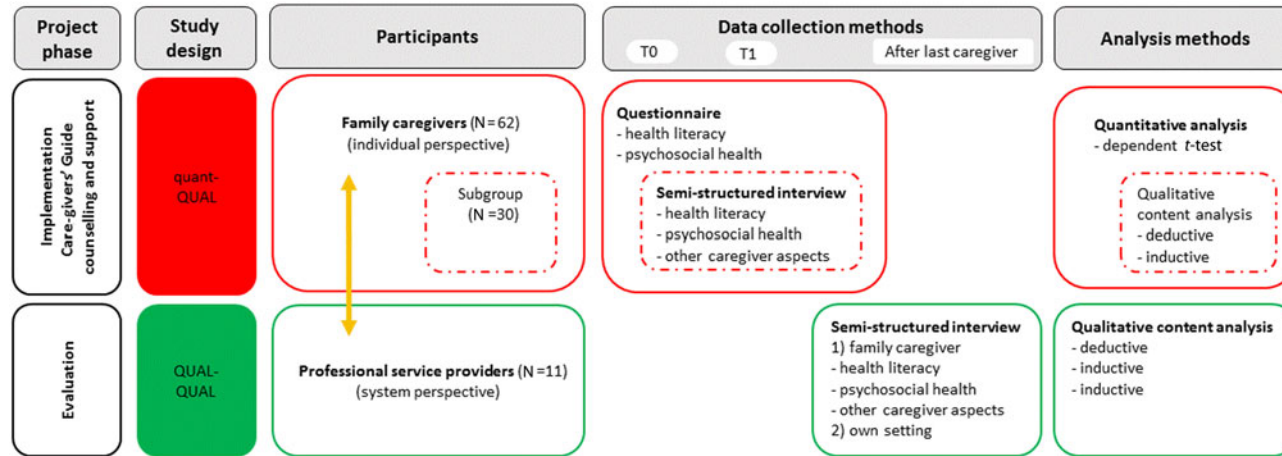


Figure 3. Evaluation design of the Care-givers' Guide support programme in the implementation and evaluation phase of the project.

Notes: The arrow between family care-givers and professional service providers depicts the interconnectedness in the system. T0: pre-intervention. T1: post-intervention.

Care-givers were aged between 28 and 83 years (mean 56.4 years, 35% > 61 years), and the majority were females (76%). They were spouses/partners (N = 38), adult children or children-in-law (N = 19), parents (N = 2), sisters (N = 2) or a close friend (N = 1). The majority of them still worked, either full-time or part-time (27 and 26%, respectively), 34 per cent were unemployed and 13 per cent were retired.

A sub-group of 30 family care-givers (15 spouses/partners and 15 adult children) was selected to participate in a post-intervention qualitative semi-structured interview. The selection criteria were that the intervention was finalised, the care-giver was interested in participating in an interview, and the care-giver possessed time and sufficient German-language skills. The aim was to gain a detailed understanding of the perceived outcomes on care-givers' health literacy and psycho-social health.

Group 2: professionals affiliated to the stroke care support system

Professionals were included in the analysis when they were enrolled in the programme through their daily work as care provider (e.g. medical doctors or case manager at the stroke unit), and took part in the referral procedure. Eleven professionals, representing the different domains of the stroke care and support system in Aachen, participated in a QUAL-QUAL study part *ex post* (Figure 3; Table 1).

After completing the programme's implementation phase, professionals reflected in a two-part semi-structured qualitative interview on the perceived outcomes of the supported family care-givers and on their own stroke care system.

Instruments and analyses

Study part 1: before–after comparison

A quant-QUAL design was applied to evaluate the outcome at the individual care-giver level. The quantitative part served as the starting point, providing first indicators for change in health status. A qualitative interview was added to further explore the perceived changes (Figure 3).

Our semi-structured questionnaire measured two indicators of change, health literacy and psycho-social health, and contained 21 items to be scored on a five-point Likert scale, ranging from 1 'very negative' to 5 'very positive' (see Appendix Table A1). Freebody and Luke's (1990) health literacy framework was used to measure health literacy on three indices: (a) 'functional health literacy' (having enough information to function in day-to-day life) was assessed with three items (Cronbach's $\alpha = 0.84$), (b) 'interactive health literacy' (having advanced cognitive and literacy skills to participate actively in daily activities and to apply new information to changing circumstances) with three items (Cronbach's $\alpha = 0.75$), as well as (c) 'critical health literacy' (most advanced cognitive skills to be used to analyse critically situations and to use this information to have greater control over life) with five items (Cronbach's $\alpha = 0.66$). For psycho-social health, we included six items to measure 'sense of certainty' (Cronbach's $\alpha = 0.82$) and four items for 'life balance' (Cronbach's $\alpha = 0.78$). SPSS 22 (Chicago, IL) was used for statistical analysis. Dependent *t*-tests were used to calculate statistical significance between T1 and T0 ($p < 0.05$). A higher score means a better outcome.

Table 1. Professional stakeholders participating in the QUAL-QUAL (qualitative) study, ordered per stroke care phase

Stroke care domain	Setting and place	Department	Position (professional background)
Acute care	University Hospital, Aachen	Stroke unit, neurology	Case manager
		Neurosurgery	Head of department (MD)
	Acute Hospital, Würselen	Stroke unit, neurology	Case manager (nurse, social worker) Social worker
Rehabilitation care	Inpatient Rehabilitation Hospital, Bad Berleburg	Patient and care-giver support services	Case manager (nurse)
	Ambulant Rehabilitation Clinic, Aachen	Psychological support	Psychologist
Home care	Home Care Service, Aachen	Home Care Service	CEO (nurse)
			Head nurse (nurse)
Intersectional and supplementary care	Communal Social Services, Aachen	Home adaption counselling services	Social worker
		Care support and counselling services	Nurse
	Medical health equipment provider, Aachen	Medical supply	Case manager (nurse)

Semi-structured face-to-face interviews were conducted with a care-giver subgroup (*see* Appendix Table A2). All interviews were digitally recorded and transcribed verbatim. Qualitative content analysis by Hseih and Shannon (2005) was applied for data analysis. The transcripts were read line-by-line by the first author, and subsequently analysed by selecting and labelling sub-themes and themes emerging from the text with both deductive and inductive approaches. First, transcripts were analysed with a deductive approach (Schreiner, 2012), starting with the indicators of the quantitative part as topics. Second, when new issues emerged an inductive approach was applied that led to the creation of new ‘sub-themes’ and ‘themes’ (Krippendorff, 2013).

Study part 2: ex post analysis

Each professional was interviewed by the first author, either face-to-face (N = 8) or via telephone (N = 3). A semi-structured instrument was utilised (*see* Appendix

Table A3) to gain a profound understanding on the perceived outcomes on both at individual and system levels.

The first author led the qualitative analysis (Hseih and Shannon, 2005). First, findings were divided in two data-sets: individual and system levels. The text reflecting on individual level was first analysed with a deductive approach (Schreiner, 2012), referring to the 'themes' and 'sub-themes' of study 1, and when new issues emerged an inductive approach was applied (Krippendorff, 2013). The text reflecting on the system level was analysed inductively only (Krippendorff, 2013), applying open coding for sub-theme and theme recognition (Hseih and Shannon, 2005).

All data collection instruments were piloted by participants from both groups regarding their feasibility, e.g. length, textual understanding and logical flow. The first author, conducting the interviews with both groups, was not involved in the counselling process at any time. The application of a semi-structured topic list allowed a dialogical means of communicating with the participant during the qualitative data collection process. Differences in data interpretation were discussed among the researchers until consensus was reached (Elo and Kyngäs, 2008). For each study part findings were triangulated, leading to a comprehensive understanding of the perceived changes on individual and system levels (Patton, 2001; Springett and Wallerstein, 2008).

Ethics

Two dimensions of ethics in qualitative research were addressed: (a) procedural ethics and (b) 'ethics in practice', defined as the everyday ethical issues that arise while doing research (Guillemin and Gillam, 2004). First, ethical approval was given by the Ethic Committee of the Catholic University of Applied Sciences North Rhine-Westphalia. In addition, the COREQ research reporting guidelines were followed (Tong *et al.*, 2007). Family care-givers received information about the study and provided written consent before data collection started. Verbal consent was obtained from all professionals participating in study 2. The second dimension was addressed by considering four important ethical research principles: (a) beneficence, (b) respect for autonomy, (c) justice, and (d) non-maleficence (Beauchamp and Childress, 1989).

Results

The two-level evaluation took four months and resulted in six outcomes. Five outcomes illustrate change on individual care-giver level, with special focus on health literacy and psycho-social health. One outcome concentrates on the perceived changes on the stroke support system level.

Outcomes at an individual level

Care-givers' perspective

Health literacy improved on all three indices, with functional and interactive health literacy showing a statistically significant increase (Table 2). Both psycho-social

Table 2. Outcome on care-givers' health literacy and psycho-social health; a quantitative pre- and post-analysis among 62 stroke care-givers supported by the Care-giver's Guide

Indicator	T0	T1	<i>t</i>	<i>p</i>
<i>Mean values (SD)</i>				
Health literacy (HL):				
Functional HL (knowledge)	3.7 (0.8)	4.2 (0.8)	4.0	0.000
Interactive HL (capability to act)	3.3 (1.0)	3.7 (0.8)	3.7	0.000
Critical HL (individual empowerment)	3.0 (0.9)	3.2 (0.8)	2.5	0.015
Psycho-social health:				
Sense of certainty	3.0 (0.8)	3.2 (0.7)	2.6	0.012
Life balance	2.8 (0.9)	2.9 (0.9)	1.2	0.26

Notes: HL levels (Freebody and Luke, 1990) were adapted to the programme. T0: pre-intervention. T1: post-intervention. SD: standard deviation.

health indices also improved: care-givers' sense of certainty was significantly increased, whereas on life balance only marginal changes were perceived.

The concepts of health literacy and psycho-social health were explored in depth in the qualitative part of the individual care-giver study part with a deductive approach (Figure 3), using the indicators of the quantitative part as topics for the semi-structured interview. The detailed results with corresponding example quotes are provided in Table 3.

Family care-givers perceived that due to the Care-givers' Guide counselling their health literacy and psycho-social health was enhanced.

Care-givers perceived a stroke-specific knowledge gain, which is considered as the first level of health literacy. Their understanding of stroke and its consequences improved, they could familiarise with the fragmented German stroke rehabilitation process (Figure 1) and felt oriented within the regional stroke support system with its support options, *e.g.* communal services (Table 3).

Care-givers noticed that their capability to act (level 2 of health literacy) improved during the counselling process:

I often could not understand the letters and requests from the health insurance. After she [counsellor] explained the topic to me I could react better on it. (Care-giver (CG) 3)

After having the necessary information (knowledge), care-givers felt enabled to collaborate with the system for both the patient and their own purposes, *e.g.* to find a suitable home care service. They started to involve themselves actively in the rehabilitation and discharge process and/or searched for further support options within the system:

She [counsellor] explained that we may apply for a disability card. I would not think about this issue by myself. (CG 53)

Table 3. Deductively exploring the outcome of the intervention on care-givers' health literacy and psycho-social health; a semi-structured interview-based qualitative study among 30 stroke care-givers (CG) supported by the Care-givers' Guide

Topic	Example quote	Sub-theme	Theme
Health literacy:			
Functional health literacy (knowledge)	'She [the counsellor] explained to me in a way I could understand the effects and consequences of the stroke' (CG 6)	Stroke-specific knowledge gain	Health literacy enhancements
	'She [the counsellor] knew the process and clarified what we could expect and how the rehabilitation process will be' (CG 49)	Familiarisation with rehabilitation process	
	'She [the counsellor] provided me with the necessary facts and told me who to approach when I face a problem' (CG 12)	Support system orientation	
Interactive health literacy (capability to act)	'As a care-giver you have to get involved in certain issues, you have to be active and back-track things. The Care-givers' Guide counsellor helped me in this aspect' (CG 55)	Proactive process involvement	
	'The Care-givers Guide prepared me for going to the communal social services and applying for the necessary support' (CG 33)	Collaboration with the support system	
	'Sometimes the applications for the health insurance contained too much administrative language which was difficult to understand. I asked her [the counsellor] to clarify them before submitting the application' (CG 3)	Search for further support	
	'She [the counsellor] told me that there is a care-giver training programme in the rehabilitation clinic in Bad Berleburg, and she assisted me to get admitted there, which was just great for me' (CG 9)	Early role preparation	
Critical health literacy (individual empowerment)	No quotes	-	-
Psycho-social health:			
Sense of certainty	'Every time she [the counsellor] was here, she explained a lot to me and answered all my sometimes confusing questions. She was very patient and over time I gained confidence to manage the situation at home' (CG 22)	Recapture of everyday life control	Psycho-social health stabilisation

(Continued)

Table 3. (Continued.)

Topic	Example quote	Sub-theme	Theme
	'In the acute phase, everybody takes care of the patient. We as relatives with our great fear and thoughts are not taken into consideration. The Care-givers' Guide counsellor took time to listen to me and my needs which reduced my fears' (CG 35)	Anxiety reduction	
	'I always had the feeling, even at midnight, that I can call her [the counsellor]. This is not like contacting an office with limited opening hours, there was always someone who can help me. That was incredibly important' (CG 49)	Accessibility of support	
Life balance	'I could not sleep well in the nights anymore since my husband came back home. My head was spinning. The Care-givers' Guide counsellor always told me that I seriously need to take time for myself. Finally, we involved a home care service and I started to relax a bit' (CG 46)	Awareness of overburdening	
	'The meetings with other care-givers experiencing the same challenges gives me so much power and joy' (CG 35)	New social contacts (peers)	

A timely stimulation for preparation for their new care-givers' role was perceived as beneficial. Proposals from the Care-givers' Guide like 'attending a communal care-giver course' (CG 35) or 'searching for a day care option' (CG 40) were considered to be very helpful.

Concerning the individual empowerment (critical health literacy – third level) due to information provision, no quotes were found in the qualitative interviews with the care-givers in Table 4.

Care-givers perceived that their psycho-social health stabilised due to the counselling process. They highlighted that counselling helped to maintain or retrieve their sense of certainty and assisted them in recapturing control of their everyday life and in taking actions to plan their 'new life', *e.g.* considering different future scenarios. Both the active listening strategy and the 'first aid guide', provided to each care-giver as an instrument in case of a possible re-infarct, were perceived to alleviate care-givers' anxiety. Counsellor accessibility was perceived as crucial in the instable new situation:

She [counsellor] always said that I should call her if I'm in trouble and this helped me to calm down my fears. (CG 38)

Moreover, care-givers stated that the counselling process helped them to find a balance in their new life. Awareness of overburdening due to a new role was raised and practical solutions were found together with the counsellor:

She [counsellor] came up with the idea that we might profit from a holiday trip and helped us though the difficult administrative process of application with the health insurance. (CG 38)

Especially towards the end of the patient's rehabilitation process, some care-givers profited from gaining new contacts within the newly established peer group:

The meetings with other care-givers that experienced the same challenge gave me so much power and joy. (CG 35)

Post-stroke, care-givers said of themselves things such as:

It was just too much. I guess if there is nobody to help, one may easily get their head stuck in the sand. (CG 35)

Most care-givers stated that emotional re-stabilisation was 'very essential' for them (CG 55). From the first counselling session, the provision of psychological first aid support, *e.g.* promoting hope, was perceived as helpful to alleviate destructive emotions. Moreover, personalised counselling was considered as 'very important' (CG 11) for taking on the new role. The personalised approach helped to gain confidence to plan a realistic future as a family. Moreover, care-givers felt supported during their grieving process.

Table 4. Inductively exploring the outcome of the intervention on other care-giver aspects that contribute to psycho-social health; a qualitative study among 30 stroke care-givers (CG) supported by the Care-givers' Guide

Example quote	Sub-theme	Theme
'In the beginning I was in a state of a shock. I was not able to think or to act. It was so important for me to get professional help' (CG 22)	Emotional re-stabilisation	Emotional wellbeing
'Our counsellor was actively stimulating us to decide what do when my father returns home. We focused on practical circumstances and because of this I could start to plan an achievable future for our family' (CG 35)	Future life orientation	
'During the counselling session, the most important part for me was to talk about my grief and to receive professional grief support' (CG 69)	Grieving process support	
'She [counsellor] helped to resolve our conflicts within our family' (CG 30)	Conflict resolution	

It is a completely different life...! How often do we sit here and tell ourselves 'if we could have our old life back...' Yes, the old life, we miss it much! (CG 5)

Finally, counselling was perceived as useful in resolving conflicts caused by having the stroke in the family, *e.g.* financial issues:

In that difficult [acute] phase I was not always in complete agreement with my sister. She [counsellor] helped us to find a good compromise. (CG 53)

Overall, the outcomes of the qualitative part suggest that individual family care-givers perceived the intervention as a great benefit.

I did not know where my head was! I was overwhelmed with fear and could barely think. Without the Care-givers' Guide I would have probably lost my head. (CG 24)

Professionals' perspective

Professionals within the stroke support system perceived in individual family care-givers (individual level) who were supported by the programme, enhancements of stroke-related health literacy and psycho-social stabilisation.

In addition to the care-givers' own perception regarding their health literacy, professionals not only perceived positive changes regarding care-givers' knowledge (functional health literacy – level 1) and capability to act (interactive health literacy – level 2) (*see* Table 5), but also outcomes on their 'individual empowerment' (critical health literacy – level 3) that were attributed to the programme (Table 6).

Professionals in all phases of the trajectory (Table 5) observed that supported care-givers were better informed about the stroke and its consequences than they expected on the basis of earlier experiences with stroke family care-givers:

Table 5. Deductively exploring the outcome of the Care-givers' Guide programme on care-givers' health literacy and psycho-social health; a qualitative analysis among 11 professionals working as service providers in the stroke support system

Topic	Example quote	Sub-theme	Theme
Health literacy:			
Functional health literacy (knowledge)	'I noticed that the Care-givers' Guide counsellor provided valuable health-related information in a care-giver-friendly language and they understood the stroke-specific issues well' (Head of department, neurosurgery, acute phase)	Stroke-specific knowledge gain	Health literacy enhancements
	'Care-givers were well informed about the process of rehabilitation' (Case manager, rehabilitation care)	Familiarisation with rehabilitation process	
	'The structured information provision included issues concerning financial infrastructural and care-giving support. She [counsellor] explained everything and distributed flyers which care-givers could read again' (Nurse, care support, communal social services)	Support system orientation	
Interactive health literacy (capability to act)	'When a care-giver was supported by this programme, they appeared to be more involved. They asked focused questions and also wanted to be involved in the decision-making process' (Nurse, home care phase)	Proactive process involvement	
	'The way of working and communicating together improved. We [families and services] were now working not against each other, but more together in order to find the best solutions for the patient and the family' (Head of home care service, home care phase)	Collaboration with the support system	
	'They [care-givers] could contact the Care-givers' Guide counsellor any time and took advantage of it, it provided them with confidence. They started to be more active' (Medical health equipment provider, home care phase)	Search for further support	
	'Care-givers were stimulated by the counsellor to participate in our training sessions already in the acute phase. So they accompanied the patient during rehabilitation and participated in this training. This was very helpful for the patient, the care-giver and also for us' (Case manager, rehabilitation care)	Early role preparation	
Psycho-social health:			
Sense of certainty	'As the counselling took place in their home environment, care-givers were much more confident in mastering the care-giving requirements' (Case manager, rehabilitation phase)	Recapture of everyday life control	Psycho-social health stabilisation

(Continued)

Table 5. (Continued.)

Topic	Example quote	Sub-theme	Theme
	'They had confidence in the Care-givers' Guide, who offered professional support to answer all their questions. Care-givers' initial anxiety was greatly reduced when care-givers were engaged in the counselling process' (Case manager, acute care phase)	Anxiety reduction	
	'Care-givers were aware of the possibility of contacting their professional counsellor at any time in case of emerging issues, which was very comforting for the care-givers' (Head of home care services, home care phase)	Accessibility of support	
Life balance	'Care-givers themselves stimulated the programme to initiate a care-giver peer group. This was really great' (Psychologist, rehabilitation care)	Awareness of overburdens	
	'Overburdening is very frequent, especially for women. I had the impression that the care-givers involved in the programme were more aware of this problem and tried to find individual solutions' (Head of home care services)	New social contacts (peers)	
Emotional wellbeing	'Experiencing a stroke in the family is a traumatic event. The Care-givers' Guide counsellor provided psychological first aid' (Psychologist, rehabilitation care)	Emotional re-stabilisation	
	'Due to the structured orientation process by the counsellor, care-givers had realistic expectations' (Case manager, rehabilitation phase)	Future life orientation	
	'There was time to grieve and cry, time to live the emotions. This was an important step for care-givers' emotional recovery' (Case manager 1, acute phase)	Grieving process support	
	'For some care-givers the interfamilial conflicts, even with the care receiver, were difficult to handle and this provoked extra peaks of emotional stress. Here the Care-givers' Guide counselled the entire family and found together suitable solutions' (Case manager, rehabilitation care)	Conflict resolution	

Table 6. Inductively exploring the outcome of the Care-givers' Guide intervention on other care-giver aspects on health literacy; a qualitative analysis among 11 professionals working as service providers in the stroke support system

Example quote	Sub-theme	Theme
'I had the impression that care-givers felt more confident in their new role' (Nurse, home care phase)	Role adaption	Critical health literacy (individual empowerment)
'Some of the supported care-givers were able to get some time off in the day-care programme. Usually, care-givers are not aware that this opportunity can be financed by the health insurance' (Nurse, home care phase)	Support network use	

Care-givers in the programme better understood the different responsibilities of the different organisations involved in the rehabilitation process. (Case manager, rehabilitation care)

Supported care-givers were also more accustomed to the broader support system and knew of more support offers, *e.g.* communal services offers.

Professionals also observed that care-givers' capability to act was enhanced earlier than in those not receiving support from the programme. They attributed this to the systematic and personalised information provision offered by the Care-givers' Guide.

I noticed that care-givers started to understand why it is important to think about the future situation already in the acute phase. Normally they are not ready for this and we have our struggles with them. (Case management 2, acute phase)

Moreover, professionals noticed that supported care-givers were earlier and more actively involved in the decision making about the future of their patient, *e.g.* discharge planning, and increasingly tried to collaborate with the support system instead of blocking or delaying necessary decisions, *e.g.* transfers to the home environment. Professionals in the home care services and the external support providers observed that care-givers prepared themselves on time for their new role and were also actively searching for support for themselves to prevent possible overburdening, *e.g.* exploring additional support options in the home environment, which was attributed to the intervention by the counsellor.

Similar to care-givers' perception, professionals observed outcomes on care-givers' psycho-social health on all three topics: sense of certainty, life balance and emotional wellbeing.

Professionals stated that during the counselling process care-givers' sense of certainty was reinforced, as they were able to plan a realistic future and gain control over their new life. They observed that care-givers' initial anxiety, *e.g.* for the future, decreased due to the conversations with the counsellor:

Care-givers had the counsellor as a first contact person if something went wrong. They told me that therefore they did not feel abandoned by the system. (Nurse, home care phase)

Moreover, professionals in all phases perceived that the supported care-givers appeared to be 'less stressed' (Psychologist, ambulant rehabilitation care) and attributed this to the accessibility of the counsellor via telephone or email.

Professionals observed a better life balance for supported care-givers. Care-givers who were supported directly from the start and through all rehabilitation phases (CBB timing) were more aware of the possible risk of overburdening than those not receiving support from the programme. Consequently, they started to search for preventive actions for themselves, *e.g.* exploring and applying for short-term care for the patient. In particular, professionals who had contact with care-givers in the home care phase noticed that supported care-givers invested in sustaining their social contacts and therefore appeared to be less isolated. In addition, some profited from making new contacts through the peer group:

Some care-givers told me that when they were more certain in their care-giving role at home, they joined the care-giver peer group and they were very content with this offer. (Head nurse, home care services)

All professionals perceived that the topic 'emotional wellbeing' was imperative for care-givers' psycho-social stabilisation, and some of them stated that the professional and early provision of psychological first aid was essential for care-givers' emotional wellbeing. 'Some care-givers are emotionally frozen, unable to act or to take decisions. Thanks to the psycho-social support of the counsellor, most care-givers gained their decision-making skills back soon' (Case manager 1, acute care), and 'when overcoming their shock status' (Case manager 2, acute care) care-givers started to organise their new life. Moreover, professionals observed that the offer of professional grieving support was perceived as very helpful by the care-givers (Table 5). Professionals perceived that the conflict resolution skills of the counsellor contributed to care-givers' emotional wellbeing (Table 5).

In addition to care-givers' perception (Table 3), especially, professionals in the later phases, *e.g.* ambulant rehabilitation or home care, observed that supported care-givers achieved an individual empowerment (Table 6).

Professionals noted that supported care-givers achieved a better role adaptation:

Supported care-givers were better equipped to understand and actively manage the care-giving process. (Medical health equipment provider, home care phase)

Moreover, an increased use of network support was observed that was considered by the professionals as important for prevention of overburdening and social isolation:

Social isolation occurs often in family care-giving. The Care-givers' Guide counsellor assured that the work is not done by only one family member. (CEO, home care services)

Outcome on system level

The programme's outcome on the system level was considered only from the professionals' perspective (Table 7).

The practitioners observed that the new programme also influenced their professional routine, the inter-institutional support, the quality of patient care and the inter-institutional co-operation.

The Care-givers' Guide programme heightened professionals' attention regarding the complexity of care-givers' needs. They perceived a professional development and resource allocation. Professionals, being in contact with the programme, observed that their view of suitable support offers in the geographic region expanded and their knowledge concerning initiatives for care-giver support provided by organisations other than their own, communal services offers for care-givers, was enhanced.

All professionals who were involved in the programme acknowledged the potential surplus value of the new family care-giver support programme within their daily work:

As the psycho-social support and co-ordination was offered to the care-giver by the programme, I could concentrate on my duty – the patient care. (Nurse, home care services, home care phase)

However, some professionals in the acute care (care manager and social worker) had to spend time recruiting potential care-givers for the new programme:

We needed to invest 15 minutes per week for preparing the recruitment list, and 20 minutes for the handover to the Care-givers' Guide. (Case manager 2, acute phase)

Professionals perceived the new care-giver programme as comprehensive support and therefore it was welcomed by them across the trajectory:

This programme was filling a significant service gap. (Social worker, acute phase)

In our clinic we do not offer care-giver counselling support. However, care-givers need clear and precise information to not get lost or overburdened by the situation, and someone who takes time for them from the start. And this is what the support programme did. (Psychologist, rehabilitation phase)

The necessary resources for providing care-giver support, e.g. time and staff, were provided by the programme, which resulted in perceived improvements of the institutional support (Table 7):

The continuous support by the Care-givers' Guide counsellor during transferal was simplifying for our work. Because many care-givers fear the situation when a patient is transferred from the rehabilitation phase to the home environment and therefore appear to be uncooperative. (Nurse, home care phase)

Table 7. Inductively exploring the outcome of the Care-givers' Guide intervention on the stroke care system; a qualitative inductive analysis of 11 interviews with professionals working as service providers in the stroke support system

Example quote	Sub-theme	Theme
'She [the counsellor] knew the system very well and helped us orient ourselves in the dynamically changing system and I've learnt a lot' (Case manager 2, acute phase)	Professionals' development	Professionals' daily routine improvements
'Due to the early, professional and structured information provided by the Care-givers' Guide, I felt less time pressure when receiving a new case' (Case manager, rehabilitation phase)	Resource allocation	
'A psycho-social support offer for care-givers was missing since we were not trained for it. Therefore, this intervention was a strong complement to our daily routine' (Case manager 2, acute phase)	Provision of comprehensive care-giver support	Augmentation of institutional support offer
'The professional, flexible, structured and needs-oriented guidance was very much appreciated by my team' (Head of department, neurosurgery, acute phase)	Resources provision (time, staff)	
'The care-givers were prepared mentally and infrastructurally for home care-giving. The transferal did not interfere with the rehabilitation outcome of the patient' (Nurse, home care services, home care phase)	Rehabilitation outcome	Securements of quality of patient care
'I have the notion that the re-hospitalisation rate of the stroke survivors was lower as the family care-giver could approach the Care-givers' Guide timely with questions if they felt unsure' (Case manager 1, acute phase)	Re-hospitalisation rate	
'The transferal process was much different compared those not supported by the programme. The information and its flow from the acute and rehabilitation care were better as the Care-givers' Guide supported this process. Consequently, patient security improved as less information got lost' (Nurse, home care phase)	Transferal process	
'Care-givers were prepared for the next rehabilitation steps and the programme reduced the transferal bottlenecks, which resulted in an increased system confidence of both care-givers and patients' (Case manager, rehabilitation phase)	Confidence in the support system	

<p>'The counsellor and I were always in contact with each other. That made us feel as companions. Our communication was characterised by a high level of trust and transparency. (Social worker, home adaption counselling services, communal social services)</p>	Communication between different institutions	Inter-institutional co-operation
<p>'In many cases you can't solve the problem alone. So we worked in a team with a common goal of finding the best solutions for both patient and care-giver' (Case manager, rehabilitation phase)</p> <p>'Through the network that was initiated by the programme we professionals got engaged with each other. This was very supportive for my daily business' (Social worker, home adaption counselling services, communal social services)</p>	Team and network building	
<p>'In complex cases the Care-givers' Guide initiated the interaction between the different services, which was very effective and innovative' (Nurse, care support, communal social services) '</p>	Interaction between different organisations	
<p>'Without the Care-givers' Guide, many care-givers would not actively search for support at my services at this moment. We had the chance to help them early enough' (Nurse, care support, communal social services)</p>	Increased and early service use	

Moreover, the counsellor invested in communication between all actors involved from different organisations, and this was perceived as helpful in completing and improving the handovers:

The Care-givers' Guide supported the stroke families since the beginning. For me it was so helpful to have someone [counsellor] who knows the family since the acute phase. She offered me a structured handover and I was much better prepared when a patient and care-giver was transferred to my services. (Medical health equipment provider, home care phase)

Due to the programme, professionals in the home care phase also perceived a strengthening of the quality of patient care. They felt that the care-giver-specific information provided by the counsellor 'completed the condensed information provided by the handover protocol' (Nurse, home care phase). Moreover, they felt that the counsellor contributed in safeguarding the rehabilitation outcome, *e.g.* having the appropriate medical equipment at home before transferal.

Professionals perceived that the counsellors' work, enhancing care-givers' stroke-specific knowledge and stabilising their psycho-social health, contributed to 'avoid unnecessary acute re-hospitalisation' (Nurse, acute care).

The new programme was a main driver in building up and maintaining an inter-organisational professional network within the region at this time. An inter-professional team-building process was started, where feedback loops provided a stimulating and positive working atmosphere:

Our communication was characterised by a high level of trust and transparency. (Social worker, home adaption counselling services, communal social services)

The new network improved the flow and quality of the communication, which was especially useful in the transferal of complex cases:

Many administrative issues were solved by using shortcuts within the system, which was beneficial for all. (Medical health equipment provider, home care phase)

Co-operation through this network was perceived as especially helpful in reducing bottlenecks, *e.g.* communications weaknesses, during transferal. The inter-institutional co-operation also activated an increased utilisation or interlinkage with the communal actors, *e.g.* communal services.

The findings from both parts of the two-level study, the multi-methodological approach and the triangulation, contributed to a comprehensive depiction of the outcomes on the individual and the system levels. Overall, both care-givers and professionals within the support system perceived a benefit from the new programme:

The structured, practical, flexible and professional guidance of the care-givers that was offered by the supplementary to the current support system was a big advantage for us and the care-givers. (Head of department, neurosurgery, acute care phase)

Discussion

A two-level multi-methodological approach was chosen to evaluate the impact of the Care-givers' Guide. The study was designed as a combination of a quantitative part measuring change in health literacy and psycho-social health in individual stroke care-givers with a semi-structured questionnaire, and three qualitative parts focusing on aspects of health literacy and psycho-social health, perceived preparedness of individual stroke care-givers and impact on the care system for stroke patients.

The results from the quantitative part on the care-giver level showed an increase in both health literacy and psycho-social health (Table 2). In the added qualitative study parts, individual care-givers reported a knowledge gain regarding stroke and its consequences, the rehabilitation process and the existing support system. They noticed improvements in their capability to act, such as proactive process involvement, collaboration with the support system, search for further support and early role preparation. They also noticed that their sense of certainty was strengthened by regaining control over their everyday life, as well as by a reduction of anxiety. Having new social contacts and being aware of the risk of overburdening due to care-giving helped to stabilise their lives. Providing professional psycho-social support enhanced care-givers' emotional wellbeing by supporting them in their future life orientation, grieving process and conflict resolution.

The effects on the individual care-giver level were further explored by including the perspectives of professionals working in the system. Interestingly, they perceived not only improvements in functional and interactive health literacy but also an individual empowerment of the supported care-givers (Table 5), which corresponds with findings of the quantitative part (Table 2). That might be due to the fact that they could reflect on their own case only and they did not see their individual empowerment processes themselves.

The effect on the system level itself was explored by interviewing professionals as being part of that system and having experienced the impact of the new programme during their daily work. Conclusions were that investing in communication and network-building activities helped in optimising the prevailing stroke support system (Table 7). Professionals perceived a positive change in their daily work within their own institutions, a strengthening of the quality of patient care and in inter-institutional co-operation.

Learning new skills

First-time care-givers, in particular, must develop new skills, e.g. practical skills, stress-coping skills and problem-solving skills, in order to interpret and analyse health information, navigate the health-care system and participate in encounters with the support system (Carlson *et al.*, 2012; Chen *et al.*, 2015). These new skills may help to adjust to the new life and its unpredictable challenges (Yuen *et al.*, 2018). Our results indicate that these skills could be developed within the relatively short period of six months. We are unable, however, to make any long-term predictions, but we expect that our care-givers felt secure enough to handle pressures or added burdens should changes occur in their own or their patient conditions.

Flexibility regarding the timing and number of sessions

In contrast with most other care-giver programmes that offer support during a specific phase of stroke survivors' rehabilitation, *e.g.* in the acute phase (Aguirrezabal *et al.*, 2013), or have limitations regarding the quantity and duration of counselling sessions (Wilz and Barskova, 2007), our programme did not set a limit on the duration of the counselling support or the number of counselling sessions, and allowed flexible choices in the actual support offer by the Care-givers' Guide counsellor. This flexibility was perceived by both care-givers and professionals as being of great benefit in enhancing care-givers' health literacy and psycho-social health. We also showed that it only required a reasonable number of sessions (mean six sessions) within a reasonable time period of six months, which is comparable with other programmes (Larson *et al.*, 2005; Schure *et al.*, 2006).

Personalised information provision

Receiving personalised information was perceived by both care-givers and professionals as fundamental in enhancing their stroke-related health literacy. In public health and health promotion, health literacy is an important indicator when aiming to improve health outcomes (Paasche-Orlow and Wolf, 2007).

Our findings show that increasing health literacy by targeted and timely information provision (Pindus *et al.*, 2018) with a personalised approach (Krieger *et al.*, 2017) led to an early and better role adaption (Tables 3, 5 and 6).

Psychological first aid

It is well known that family care-givers experience immediate high emotional stress levels from the start of their new role (Grant *et al.*, 2014). Our Care-givers' Guide counsellor offered psychological first aid as part of the support programme, which was perceived by both care-givers and professionals as essential in stabilising care-givers' psycho-social health. We found only one earlier publication, offering a one-session crisis intervention to stroke survivors and primary care-givers in the inpatient rehabilitation setting (Palmer *et al.*, 2004). Unfortunately, the effect of their intervention was not reported.

The family care-giver as part of the system

Inter-disciplinary co-ordination between the different care providers, as well as co-ordinated discharge planning and case management, with focus on the needs of both the patient and their family care-givers is important (Cameron *et al.*, 2008). However, we observed that our family care-givers were overlooked by the professionals within our setting. Our professionals stated that they lack training, time and skills to involve care-givers or provide stroke-specific knowledge, and suggested including the family care-giver in future stroke care guidelines, as was suggested by Ris *et al.* (2019).

Holistic view

From the inception of our project we considered the German stroke rehabilitation trajectory as a holistic system. Our programme explicitly invested in the system by building up a professional network and improving the communication between the different actors in the support system (Figure 2; Krieger *et al.*, 2019). As the programme progressed, the professionals involved in the service provision started to acknowledge care-givers as part of the rehabilitation team, which was perceived as a first step in system optimisation. The ‘facilitating CBBs’ were perceived by the professionals as helpful by improving the communication lines, empowering individual professionals, *e.g.* by gaining a better understanding of the entire support system, as well as the broader system, *e.g.* by stimulating direct interactions between different organisations within the setting. Especially the professionals in the home care phase observed that the quality and continuity of care for the stroke survivor in the home environment got better in the course of the project due to ‘personalised’ transfers, *e.g.* obtaining detailed information on the care-givers’ needs.

Strengths and limitations

In this evaluation we aimed to gain a comprehensive understanding of the outcomes of the Care-givers’ Guide programme on both the individual care-giver as well as the stroke service provider level, interconnected with each other. We chose an intricate study design with four connected parts and two different methodologies (quantitative as well as qualitative). We were limited in the quantitative part by the relatively small number of participants and the use of a questionnaire with a limited scope of health indicators. However, this quantitative part only served as a starting point for the larger qualitative part, which took up the most time and resources of the project team and the participants. We showed that using a mixed-methods approach was feasible and appreciated by the individual care-givers, as well as by the professionals. Methodological pluralism (Morse, 2015) and the combination of a deductive–inductive approach (Graneheim *et al.*, 2017) during data analysis enabled us to explore the outcomes of our complex programme in depth. However, as complex interventions are strongly context- and time-dependent (Campbell *et al.*, 2007; Datta and Petticrew, 2013), replication may be challenging. Nevertheless, our approach can serve as an example for evaluation studies of complex interventions.

Conclusion

As complex interventions may have outcomes on different levels, a comprehensive evaluation is required. This paper provides evidence of the Care-givers’ Guide benefits at both individual and system levels.

On an individual level, we detected outcomes on care-givers’ health literacy and psycho-social health. Care-givers observed improvements in their own stroke-specific knowledge (functional health literacy) and capability to act (interactive health literacy). Professionals perceived improvements in care-givers’ individual empowerment (critical health literacy). The provision of psycho-social support

was perceived by both the programme's end-users (care-givers) and the service providers (professionals) as beneficial for care-givers' psycho-social health. Care-givers' 'sense of certainty' and 'life balance' were strengthened and their 'emotional wellbeing' enhanced.

At a system level, the existing stroke support system felt optimised by investing in communication and network-building activities. The Care-givers' Guide influenced the professionals' daily routine, the institutional support offer, the quality of patient care and inter-institutional co-operation.

The application of a two-level interconnected mixed-methods approach, as well as the deductive and inductive data analysing methods, added significantly to our understanding regarding the complexity of outcomes on both individual care-givers as well as on the stroke support system.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S0144686X20000665>

Acknowledgements. We thank all family care-givers and professionals for their time investment and contribution in this evaluation. The presented study stems from the research project 'The Care-givers' Guide', conducted under the direction of Prof. Dr Johannes Jungbauer, at the Catholic University North-Rhine Westphalia, Germany.

Author contributions.

All authors revised the article critically for important intellectual content and approved the final version. FF and ED participated in analysing and interpreting data. ED contributed to the design of the manuscript. TK contributed to the data collection and primary analysis, and the conception, design and drafting of the manuscript.

Financial support. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Conflict of interest. The authors declare no conflicts of interest.

Ethical standards. The board of the University of Applied Sciences North Rhine-Westphalia and the Ethics Committee of the University Hospital Aachen provided ethical approval.

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Appendix

Table A1. Pre- and post-intervention questionnaire from the Care-givers' Guide (adapted English version)

Indicator and index	Questions (specific variables)
Health literacy (HL):	
Functional HL (three variables)	<ul style="list-style-type: none"> • Regarding the stroke disease of my relative, I feel well informed. • I know what happens during my relative's treatment or rehabilitation and how I can support the recovery process after stroke. • I know who to contact if I need help.
Interactive HL (three variables)	<ul style="list-style-type: none"> • Lately, I feel like I'm powerless and helpless. • In the face of post-stroke problems, I feel totally overwhelmed. • I am confident that I am well prepared to meet the challenges related to my relative's care and support after stroke.
Critical HL (five variables)	<ul style="list-style-type: none"> • To cope better with the situation after the stroke, I ask other people for advice and help. • I thought in detail about what I can do to improve the situation. • I did something to relieve or distract myself. • I also try to find something good in what has happened lately. • I try to find hope in my faith.
Psycho-social health:	
Sense of certainty (six variables)	<ul style="list-style-type: none"> • When I think about the future right now, I'm afraid of the worst. • I'm very worried that my loved one might need continuous help and care after the stroke. • At present, I often ponder, and my thoughts turn in circles. • I also feel my fears and worries physically (e.g. shaking, palpitations, abdominal pain). • I am afraid that due to the health situation of my relative we will face financial bottlenecks. • I fear that my relative will change their personality a lot because of the stroke.
Life balance (four variables)	<ul style="list-style-type: none"> • My own needs are currently missed out. • Currently, I have too few opportunities for rest and relaxation. • At the moment I have barely time for social contacts and activities (friends, colleagues, etc.) • Despite all the problems caused by the stroke, I also experience positive feelings in everyday life (e.g. joy, contentment, gratitude).

Table A2. Topic list for semi-structured interviews with stroke family care-givers

Warming up	1. Can you briefly describe the situation after the stroke happened for you? (feelings, thoughts, questions)
Reflecting on the intervention	2. What changed when the Care-givers' Guide was approaching you for the first time?
	3. What did the Care-givers' Guide offer you in the counselling, and what exactly was helpful for you? (information, psycho-social support, emotional strengthening, security, orientation)
	4. How would you describe the work of the Care-givers' Guide?
	5. When did you require the most support from the Care-givers' Guide? Why?
Closing down	6. What could be improved in the future? (scope, sustainability)
	7. Would you recommend the Care-givers' Guide?

Table A3. Topic list for semi-structured interviews with professional stakeholders

1. How did you experience the work of the Care-givers' Guide in your practice? (critical reflection concerning the interventions' conceptual building blocks: content, human resources, timing, approach, setting, communication, networking, social safety-net)
2. What effects did the Care-givers' Guide intervention have in your daily work? (own profession, department, support system, stroke survivor)
3. What effects did you perceive on family care-givers when these were supported by the intervention?
4. Are there any suggestions for improving the current intervention?

Cite this article: Krieger T, Feron F, Dorant E (2022). Two-level multi-methodological evaluation of a new complex primary support programme for stroke care-givers in Germany. *Ageing & Society* 42, 1–31. <https://doi.org/10.1017/S0144686X20000665>