INTERNATIONAL JOURNAL OF HEALTH PROFESSIONS
Volume 11, Issue 1, 2024, Pages 155–165, ISSN 2296-990X, DOI: 10.2478/ijhp-2024-0012

Accompanying Persons in Child and Adolescent Rehabilitation – what role do they play? Qualitative interviews with therapeutic staff and carers

Begleitpersonen in der Kinder- und Jugendrehabilitation – welche Rolle nehmen sie ein? Qualitative Interviews mit therapeutischem Personal und Sorgeberechtigten

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Received 24 August 2024, accepted 11 November 2024

Abstract

Background: Medical rehabilitation for children and adolescents in Germany has been strengthened in recent years, including facilitated admission of parents/caregivers, leading to an increase in the number of 'accompanying persons' in the rehabilitation setting. The aim of this study was to explore the roles of accompanying persons in rehabilitation, taking into account the perspectives of different stakeholders.
Methods: Semi-structured interviews were conducted with 12 accompanying persons at the beginning and the end of rehabilitation, as well as 18 healthcare providers with different areas of expertise. Data were analysed deductively and inductively using framework analysis.
Results: In addition to the topics of pre-rehabilitation-information and the general conflicting character of accompanying persons, three role categories could be identified within the rehab setting: Accompanying persons as *child-caregiver*, *self-caregiver* and *clients of care*. These roles are associated with different demands, needs and tasks.
Conclusions: Our findings suggest that the concept of ‚accompanying person' should be further developed. Both clinical staff and accompanying persons themselves should become more aware of the different role-requirements. Greater consideration of the different needs and resources of accompanying persons is essential to provide sustainable support for both children and caregivers.

Abstract

Hintergrund: Die medizinische Rehabilitation für Kinder und Jugendliche in Deutschland wurde in den letzten Jahren u.a. durch die erleichterte Mitaufnahme von Eltern/Betreuenden gestärkt. Dies führte zu einem Anstieg der Zahl der „Begleitpersonen" in der Rehabilitation für Kinder und Jugendliche. Ziel dieser Studie war es, die Rollen von Begleitpersonen in der Rehabilitation zu untersuchen, wobei die Perspektiven von verschiedenen Akteur:innen berücksichtigt wurden.
Methoden: Es wurden semistrukturierte Leitfadeninterviews mit 12 Begleitpersonen zu Beginn und zum Ende der Rehabilitation sowie mit 18 Klinikmitarbeiter*innen aus unterschiedlichen Fachgebieten geführt. Die Daten wurden inhaltsanalytisch kombiniert deduktiv und induktiv mittels der Frameworkanalyse analysiert.
Ergebnisse: Neben den Themen der Vorab-Informationsvermittlung und dem generellen Konflikt bzgl. der Rolle der Begleitpersonen konnten der Rollenkategorien im Rehabilitations-Setting identifiziert werden: Begleitpersonen als *Kinderbetreuer:innen*, *Selbstfürsorgende* und *Fürsogeklinet:innen*. Diese Rollen sind mit unterschiedlichen Anforderungen, Bedürfnissen und Aufgaben verbunden.
Schlussfolgerungen: Die Ergebnisse der Studie legen nahe, dass das Konzept der „Begleitperson" einer Weiterentwicklung bedarf. Das Bewusstsein für die unterschiedlichen Rollenanforderungen sollte sowohl bei Klinikmitarbeiter:innen als bei den Begleitpersonen selbst geschärft werden. Eine stärkere Berücksichtigung der unterschiedlichen Bedürfnisse und Ressourcen der Begleitpersonen ist für eine nachhaltige Unterstützung sowohl der Kinder als auch der Begleitpersonen selbst von zentraler Bedeutung.

Keywords

Children rehabilitation – accompanying person programme – parents – health care professionals– role conflicts – qualitative interviews – children with chronic illness

Keywords

Kinderrehabilitation – Begleitpersonenprogramm – Eltern – medizinisches Fachpersonal – Rollenkonflikte – qualitative Interviews – Kinder mit chronischer Krankheit

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INTRODUCTION

In recent decades, there has been a shift in focus in Germany from acute to chronic illnesses among children and adolescents. This has influenced the growing importance of rehabilitative measures for children and adolescents (Petermann et al., 2017; Schlack & Brockmann, 2014). According to data from the baseline survey of the KiGGS study (Child and Adolescent Health Survey of the Robert Koch Institute), 39% of children and adolescents have a chronic illness (Neuhauser & Poethko-Müller, 2014).

Sick children (and adolescents) are dependent on care from a family or family-like context (Thyen, et al., 2021). The care and illness management of chronically ill children and adolescents requires a high level of support and care from families and/or close carers and also presents them with physical and psychological challenges, especially in coping with everyday life (Wiegand-Grefe et al., 2022). The qualitative study by Jürgensen et al. 2017 shows that the rehabilitation goals of families with chronically ill children are primarily aimed at strengthening family resources (Jürgensen et al., 2017).

The roles that parents and other caregivers take on, both in care and support in the home environment and during a rehabilitation program, are heterogenous. As part of a scoping review, Smith et al. (2021) found that a variety of roles of parents of children with chronic illnesses can be derived during a rehabilitation intervention (Smith & Samuels, 2021a). The role that parents take on depends on the individual parents and their situation (Forsingdal et al., 2014; James & Chard, 2010).

The strengthening of medical rehabilitation services for children and adolescents in Germany planned by the German Government is one of the aims of the Flexible Pensions Act ("Flexirentengesetz"), which came into force in 2017, and includes the extension of the "right to be accompanied by an accompanying person (AP) if this is necessary for the implementation or success of the service [...]." (§ 15a SGB VI). AP are usually parents or, in rare cases, close carers of chronically ill children and adolescents.

The "Rehabilitation 2019" statistics show that in 2019, 57% of children (compared to 34% in 2014) were accompanied during their rehabilitation stay by a person with custody (Deutsche Rentenversicherung, 2019). This could indicate an increasing family-orientation in child and adolescent rehabilitation (Thyen et al., 2021).

The concept of taking accompanying persons into rehabilitation for children and adolescents must be distinguished from the concept of "family-orientated rehabilitation" which is a fully inpatient aftercare programme integrated into standard care for severely chronical ill children, siblings and their parents (Leidig & Maier, 2021).

The inclusion of accompanying persons must also be distinguished from the so-called "parents-child measure", which falls within the responsibility of statutory health insurance and focusses on the parent who is at risk of illness or already ill. In this case, the child is only an 'accompanying person' and is not treated (Widera et al., 2017).

The procedure laid down in the legal text (Section 15a SGB VI) for bringing accompanying persons into child and adolescent rehabilitation places the child at the centre of the treatment. The AP has no need for treatment of their own and should be guided as a "co-therapist" (Widera et al., 2017).

In Germany, the implementation of accompanying person programmes (APP) has been piloted in projects, however there is still no empirical data on the design and impact of these programmes or on the perception and satisfaction of participants in the German-language literature.

How accompanying persons can be involved in the rehabilitation process of children and adolescents in the most beneficial way possible and how this can be adequately realised is not further specified in the legal text. As part of the "accompanying persons key issues paper" adopted in January 2022, rehabilitation clinics can develop concepts for accompanying persons by the end of 2024 and implement them with financial support after review by the lead pension insurance provider (Deutsche Rentenversicherung, 2021).

The active involvement of parents, respectively close family caregivers, in children's therapy is also used and discussed in the international context. The naming and design of programmes that involve parents varies from country to country, depending on the indication and the legal requirements.

Thus, the concept of family-centred practice appears to be a widely used framework internationally. A family-centred approach is characterised by activities in which information is shared so that informed decisions can be made. It can address families' priorities and choices, and collaborative partnerships between families and clinical staff are considered essential (King et al., 2022).

In the family-centred approach from Ontario, for example the optimal development of the child takes place in a supportive family context. The active participation of parents in the rehabilitation programme includes, among other things, involvement in all therapeutic processes and the exchange of information for further therapeutic activities in the home environment (Phoenix et al., 2020).

In addition to the core values of the family-centred approach, there is an increasing shift from impairment-based interventions to interventions that focus on

improving social participation. This shift can be partly related to the International Classification of Functioning, Disability and Health for Children and Youth, which places great emphasis on the interaction between the child and their social context (WHO, 2016). Even though the family-centred care model, which is widely used internationally and considered best practice, cannot be applied in all its aspects to the APP here in Germany, both models still have something in common. Namely, the active involvement of parents or close caregivers in the rehabilitation of their children, which has a positive influence on the empowerment of parents and close caregivers (Kruijsen-Terpstra et al., 2016; Vroland-Nordstrand et al., 2018).

As international research has shown, parents take on several roles in the rehabilitation of their children such as *Bringer*, *Supporter*, *Informer*, *Observer*, *Learner*, *Implementer*, *Adaptor*, *Collaborative decision-maker*, *and Advocate* (Smith & Samuels, 2021), each of which is associated with a different set of expectations and tasks. When it comes to the specific concept of 'accompanying person', the different roles of parents or close caregivers in rehabilitation may be further explained, or the behavioural expectations may also change in part due to the predetermined order implied by the theoretical concept (Deutsche Rentenversicherung, 2021). This paper reports on qualitative data pertaining to the role and involvement of caregivers in context of clinical children and adolescent rehabilitation of two rehabilitation clinics in Germany, which have been implementing APPs since 2018 and 2021. The core elements are training, education and advice on conflicts in the everyday context.

The aim was to explore the main target group of the APP to be evaluated, namely the AP themselves, both from their own perspective and from the perspective of the clinical staff involved.

Qualitative interviews were conducted with AP and clinic staff. This interview study is embedded in a superordinate study, which is funded by the German Pension Insurance Rhineland-Palatinate for a period of 36 months.

METHODS

Study design

To find out how both accompanying persons and rehabilitation clinic staff perceive the programme, we conducted semi-structured qualitative interviews.

Methods, data-analysis, and findings were reported in accordance with the COREQ-Guidelines (Tong et al., 2007). The qualitative interviews were embedded in a parallel mixed methods design in which, in addition to the qualitative data, the effectiveness was also examined via a questionnaire survey.

Participants

Recruitment took place between October 2022 and March 2023. We included various experts from the rehabilitation clinic staff (moto therapists, ergo therapists, psychologists, paediatricians, nurses, social workers, physiotherapists) who are part of the APP and work in the rehabilitation clinics at least 2 years. Purposive sampling was chosen to achieve the greatest possible heterogeneity of perspectives.

The AP were interviewed at the beginning and at the end of their stay, which was between four and six weeks. The sampling of the accompanying persons was continuous and rather pragmatic. The study nurse employed by the project provided information about the project and the APP at an information event when the AP arrived. In this context, the study nurse acted as gatekeeper by inviting all accompanying persons to an interview and motivating them to participate. Despite the pragmatic approach, the aim was to obtain a sample as heterogeneous as possible. In addition, the study team created posters to raise awareness of the study and to recruit participants for the study and specifically for participation in the interviews. These were displayed in the clinics and included as flyers in the AP folders.

Interview guideline

Both semi-structured interview guidelines were created in an iterative process in teamwork (JS, LK, SF). The guidelines consisted of several thematic blocks, a narrative-generating question and corresponding maintenance and control questions (*see appendix 1, 2 and 3*). Before the interview began, socio-demographic data of the participants, such as age, gender, number of children, living situation, etc., was surveyed and documented by the interviewer.

The applicability of the guidelines was tested in a pilot interview. During the interviews and after reviewing the first transcripts, the guidelines were thematically reviewed and sharpened. No changes relevant to the content were made during the interviews.

Data collection

The Ethics Committee of Charité – Universitätsmedizin Berlin (EA2/297/21) approved the study. Informed consent was obtained prior to data collection.

The expert interviews were conducted via telephone by two trained qualitative researchers (LK, SF) with different professional backgrounds (social scientist / health scientist, psychologist) and ranged from 35 to 74 minutes. The AP were also interviewed via telephone but also partly in presence, by one trained qualitative

Table 1: description of the sample of accompanying persons and health care professionals.

accompanying persons characteristics	
relationship to child	*biological parent: 11; grandparent: 1*
gender	*female: 8; male: 4*
mean age (in years)	*44 (range: 33 – 64)*
employment	*in employment: n=10*
parenting situation	*single parent: n=2*
own disease	n=5 no disease, n=2 mental disease, n=4 several physical diseases and n=1 mental and physical disease
middle age	*9 years (range: 3-14)*
health care provider characteristics	
middle age (in years)	43 (range: 25 – 57)
gender	female: 16; male: 2
work experience in the respective clinic (in years)	11 years (range: 2 – 30)

researcher (JS) (health scientist / Master Public health) with support of the study nurse (MS) (sport scientist and movement therapist in one of the cooperating study-rehabilitation clinics) and ranged from 10 to 33 minutes. To our knowledge, the interviewees were alone during the telephone-interviews, 2 participants were in company of their infants. Field notes were taken during the interview. Interviews with the AP at two different points in time were each conducted using two different guidelines; another was developed and used for clinical staff.
No repeat interviews were carried out. Data were collected until saturation of ideas was reached. Interviews were audio-recorded and transcribed (MS; transcription office) verbatim in anonymised form. Anonymisation was achieved by numbering and, in the case of clinic staff, by naming their job title, which we have omitted here. The transcripts were not returned to the interview participants.

Data analysis

All identifying information was removed from transcripts The interviews were analysed deductively and inductively using framework analysis (Gale et al., 2013) (*see appendix 5 and 6*). The MAXQDA data management programme (Version 2022, VERBI GmbH) supported the analysis.
The codesystem and the coding of the respective interviews were developed and analysed by two of the researchers (LK, JS). Due to the anonymisation of the interview data, it was not possible to conduct a case analysis over time. Participants were not asked to provide feedback on this data.

Research team and reflexivity

The participants had no knowledge or relationship with the researchers prior to the interviews. Six accompanying person-interviews were conducted by the study nurse, who knew the accompanying persons before from her work as a movement therapist. The participants knew about the aim of the study, which was to evaluate the programme from different perspectives. Participants were aware of the interviewers' work on the research project, but were not actively informed of their professions (academic education).
The research team was and is involved in several studies dealing with the rehabilitation of children and adolescents. All researchers are of female sex and gender.

RESULTS

28 participants have been interviewed for this study, which included 18 healthcare providers and 12 AP (*see Table 1*).
Topics are each underpinned with selected quotations. The quotations to the specific sections of the article can be found in appendix 4. The quotes have been abridged for better readability.
The interviews with both AP themselves and clinic staff showed that AP were confronted with different role demands during the rehabilitation stay; these results could be deduced inductively.
Three care-related categories were developed, within which their social role can be understood: As close caregivers and usually legal guardians of the rehabilitants, the AP were responsible for their children's health and provided various forms of care within the clinic processes. We refer to this as *child-caregiver* in contrast to their role as *self-caregiver*, where the focus was on their own needs during the rehabilitation stay. At the same time, the AP were clients of the rehabilitation clinic, which enhanced their skills as caregivers for the rehabilitants, providing them with training and counselling, and involving them in the children's therapies (as part of the accompanying persons programme). We refer to this aspect of their role

as *clients of care*. These three aspects of the role can be understood schematically, overlap, and cannot be clearly separated in every aspect. Categorisation helps to make role conflicts visible.

Pre-rehabilitation Information and awareness of roles and tasks

In order to understand how AP perceived their roles in rehabilitation and to what extent they were aware of care-related aspects in advance, it was necessary to focus on the information situation before the start of rehabilitation. This concerns both the information that AP received from the clinics before rehabilitation, and the information that clinic staff had about the AP before the start of rehabilitation. Among other things, this information was central for the localisation of the AP themselves and, conversely, it was important for clinic staff to have prior information about companions to be able to assess what they can expect from them and what their needs are.

The AP received information about their children's stay at the rehabilitation clinic. They were not informed in advance about their own participation or about the significance of the programme for themselves and the care of their child. Although the AP were not informed in advance about their own participation, they were positive about the programme. *(See quotation Q1_1)*

Many of the accompanying persons interviewed reported that they had benefited from being informed about the organisation of the rehabilitation stay and in particular about their role in the process. Involving accompanying persons at an early stage would have been helpful both for mental preparation and for practical implementation on site. *(See quotation Q1_2)*

The clinical staff also saw a disadvantage if the accompanying persons were not informed in advance about their participation in the programme. In their opinion, accompanying parents could inform themselves in advance on the clinic's website. *(See quotation Q1_3)*

From the perspective of the clinic staff, the lack of information and awareness of what happens in the clinic led to the accompanying persons having false expectations of the programme or of their stay. As a result, the concept could not live up to its principle of cooperation between accompanying persons and children. *(See quotation Q1_4)*

The interviews with the clinical staff also showed that they were aware of the need for comprehensive advance information about the accompanying persons. They had Information about diagnoses, outpatient therapies or employment and most of them said, they collected relevant information in face-to-face conversations at the beginning of the rehab, to find out what the AP needed and could achieve. *(See quotation Q1_5)*

Child-caregiver

Expectations for the rehabilitation stay

Most of the accompanying persons interviewed saw themselves mainly in the background; their child took priority. They only had expectations of the rehabilitation stay in terms of improving their child's state of health. However, they did not formulate any expectations of their own stay as an AP before starting rehab. They were rather surprised at the opportunity to take part in activities themselves. In this context it was also emphasised that this was probably due to the fact that the accompanying persons did not know in advance that they themselves would be actively involved in the child's rehabilitation. *(See quotation Q2_1; Q2_2)*

Dealing with hope and disappointment

The complex situation of the accompanying persons in the context of child-rehabilitation, of which they were often unaware in advance (see paragraph 'pre-rehabilitation information and awareness of roles and tasks'), from the perspective of the clinical staff also entails different expectations regarding the stay in the rehabilitation clinic. The clinical staff observed various expectation-related levels. In their role as close caregivers and/or parents, they often observed accompanying person's hope for a significant improvement in the child's state of health, also because some of them have already been through a long ordeal. However, this hope could not be fulfilled in all cases; therefore clinic staff also felt confronted with their disappointment. *(See quotation Q3_1; Q3_2)*

Supporting the clinic organisation by taking on various tasks

One aspect of their rehab-stay was that they took the children to and from therapy. In this way, they also took on a supporting role for the APP, as this care of the children could not be provided by the clinic staff. They also took care of their children by getting them up and dressed, eating together in the canteen, spending free time with them, and getting them ready for bed. As they were accommodated in a shared room, they had little privacy or space to themselves. *(See quotation Q4_1; Q4_2)*

Self-caregiver

Accompanying persons also took on the role of self-caregiver. This role consisted mainly of their own participation in the APP. In addition to the opportunity to participate in the courses and seminars offered as part of the programme, their participation also included contact

and exchange with other accompanying persons; this interaction

Interaction with other accompanying persons

The exchange with other caregivers was described as very valuable. On the one hand, because it made them feel less alone in dealing with their child's illness and, on the other, because they were able to talk to other affected persons about similar problems and give each other advice and tips. There is also a noticeable sense of cohesion and connection among the accompanying persons. *(See quotation Q5_1)*
The shared experiences within the caregiver programme and the associated group processes had effects on the individual. Several clinic employees observed that awareness of mental illness only arose through exchange with other AP with similar symptoms. They could also learn from each other and gain understanding of their complex situation, which may not be recognised or understood by others in their everyday lives at home who are not affected. *(See quotation Q5_2)*

Support among the accompanying persons

Informal interaction with other accompanying persons, which took place outside of the lectures and training sessions led by doctors and therapists, was only possible to a limited extent. During the time when the AP were not involved in the children's rehabilitation programme, the children were not cared for either. Partial additional childcare provided by the clinic staff could give the caregivers the opportunity to exchange ideas with other AP outside of the clinic routine. Beyond that, they helped and supported each other, for example by sharing experiences and knowledge, but also by looking after each other's children during the rehabilitation period. *(See quotation Q6_1; Q6_2)*

Clients of care

The framework conditions of the APP stipulated that the accompanying persons have an exclusively accompanying function and that all treatments/interventions they received must be related to the child's rehabilitation. Although they are not patients in the classic sense, they could be seen as clients of care seeking advice and help from the clinic to find a way of dealing with their child's illness against the background of their own everyday challenges.

Exhaustion among the accompanying persons

It became clear that most of the accompanying persons started their stay in rehab with a high level of exhaustion. On the one hand, this exhaustion was the result of everyday stress, particularly in dealing with the child's chronic illness, and on the other hand, it was partly influenced by their own (mental) illness. *(See quotation Q7_1; Q7_2)*
Exhaustion and stress were also directly mentioned in interviews with clinic staff. From their point of view, stressors ranged from illness to socio-economic disadvantage, difficult family situations or excessive demands in everyday life; in some cases, all of these factors came together. The clinic staff reported that some AP have what they consider to be an excessive desire for rest and relaxation, which the clinic stay does not provide. These needs are often considered inappropriate for the rehabilitation stay by the clinic staff. *(See quotation Q7_3; Q7_4; Q7_5)*

Mental health of the accompanying persons

In the interviews, it was also noticeable that the clinic staff frequently mentioned the issue of mental illnesses of accompanying persons. The conspicuous emphasis on mental illness may also be due to the fact that these accompanying persons complicated the process in the clinic because they had special needs that were difficult to meet within the framework of the programme, and led to excessive demands and feelings of powerlessness among clinic staff. The issue of shame about mental disorders was mentioned as a problem that led to accompanying persons hiding them and therefore not receiving the appropriate help.
The accompanying persons themselves also mentioned mental health problems related to the stress and excessive demands they brought with them to the clinic from their everyday lives.
The topic of 'own mental illness' did not come up in the interviews with the accompanying persons, although three (of seven who reported one or more own illnesses) reported having a mental illness themselves in the demographic data query at the beginning of the interview. *(See quotation Q8_1; Q8_2)*
Accompanying persons with mental illnesses may be less able to fulfil the roles assigned to them by the APP. The interviews showed that the clinics tried to provide support in such cases by e. g. making the accompanying persons aware of their problems and referring to outpatient support services that could be offered after rehabilitation. However, there was no provision for psychological treatment as part of the rehabilitation stay. *(See quotation Q8_3; Q8_4; Q8_5)*

Offers and needs

The needs expressed by accompanying persons were primarily individual. These included, for example, the

desire for more psychological support and assistance with bureaucratic procedures, as well as the desire for childcare by clinic staff. (*See quotation Q9_1)*
Clinic staff also reported that caregivers asked for more individualised treatment elements, such as individual psychotherapy sessions or more varied recreational activities. However, they repeatedly emphasised that the focus was on the children's treatment and that the accompanying persons' satisfaction was of secondary importance. At the same time, it became clear that it was particularly difficult for the clinic's therapy planning and logistics to integrate the accompanying persons individually and appropriately into the rehabilitation process. The dissatisfaction of the accompanying persons can also be frustrating for the clinical staff. (*See quotation Q9_2)*

The conflicting character of the idea of 'accompanying person'

The interviews revealed that the different roles the accompanying persons took on as part of the concept sometimes competed with each other. The clinic staff were aware of the contradictions in the sense that it was productive to gain an insight into and build on the relationship and family circumstances, but on the other hand there should also be more focus on the accompanying persons themselves. If they did not meet the challenges posed by the roles assigned to them, they could become an obstacle in the rehabilitation process. In some cases, the inclusion of accompanying persons in rehabilitation made everyday life at the clinic more difficult and accompanying persons were seen as a burden. (*See quotation Q10_1)*
In order to better fulfil the idea of holistic treatment of the AP and children, clinic staff believed that more resources needed to be made available. *(See quotation Q10_2)*

DISCUSSION

Semi-structured interviews were conducted with clinic staff who were responsible for the child's therapy, as well as for the therapy and care of the accompanying persons, and the AP themselves, who accompany their children to rehabilitation and take part in measures themselves, as part of an APP.
The AP's role in rehabilitation and the APP is multidimensional, involving behavioral patterns tied to a specific status (Halkowski, 1990). The focus is on how the AP negotiates this role, with social roles viewed as complementary (Parsons, 1991).
Their own perception of their role seems to depend on a number of factors. Influencing factors include the early transfer of information about their active involvement in the child's rehabilitation through participation in the APP, and their own expectations of their stay in the rehabilitation clinic in this regard, but also their needs and wishes regarding their own participation in the APP during the course of their rehabilitation stay. It must also be taken into account that, as carers of mostly chronically ill, they generally tend to be exposed to increased stress (Cousino & Hazen, 2013).
At the same time, clinic staff bring with them requirements and expectations of the role of APs that are characterised by individual values and narratives and which must also take into account the structural conditions. The care-related roles developed in advance by the authors (child-caregiver, self-caregiver and clients of care) can be superimposed on the influencing factors.

Need for information and communication

Right at the beginning of the interviews, it became clear that the AP had no information about their own participation in the APP. This meant that they were both mentally and practically unprepared for their activities during the rehabilitation stay. The resulting lack of preparation for their stay may have led to poorer adherence to the APP. The need for information from parents, which is also central to the internationally established family-centred concept in the context of a collaborative partnership (Kruijsen-Terpstra et al., 2016; Phoenix et al., 2020), is relevant at various levels: The transfer of information before the start of rehabilitation, information during the rehabilitation stay and the transfer of information for the transfer to everyday life.
The fact that the AP were not informed in advance is viewed rather negatively by the interviewees and leads to the wish for more information to be provided. Other international studies also confirm the rather negative evaluation by both parents and health professions of the transmission of information in the context of family-centered rehabilitation programmes (Cunningham & Rosenbaum, 2014; Darrah et al., 2012). Consequently, a lack of information can lead to reduced collaboration between parents and health care professions. This may result in a limitation of their ability to make specific decisions in the sense of shared decision making (Stefánsdóttir & Thóra Egilson, 2016). The lack of information may be a far-reaching consequence of the lack of communication and information transfer between the different care providers (Stumm et al., 2023) beyond the rehabilitation facility.
A systematic review and meta-analysis of research findings examines the 'Measures of Processes of Care' (MPOC-20) on the perceptions of parents with children with physical disabilities of family-centered practice, in which the opportunity for communication with the healthcare providers seemed to be important (Almasri et al., 2018). In their interview study with patients, family members

and healthcare professionals, Bamm and Rosenbaum (2008), on the other hand, found that family members considered communication and access to information to be most important, whereas health care professionals focused on education with regard to the child's illness (Bamm et al., 2015).

Child-caregiver

In the interviews, the APs did not formulate any expectations for themselves regarding the programme and the rehabilitation stay, but instead focused on the hope of improving their children's health. However the clinic staff described the problem of the APs' implicitly too high expectations in connection with the improvement of the child's state of health, which they were unable to meet. These results go in line with the findings from the interview study by Phoenix et al. (2020), where the only expectation and hope parents expressed was a 'quick' recovery of their child (Phoenix et al., 2020).

From the different perceptions of the accompanying persons and the clinic staff regarding the expectations for participation in the programme and the children's rehabilitation stay, it can be concluded that a clear assignment of tasks and expectations at the beginning of the rehabilitation stay could contribute to the children's rehabilitation success as a supportive aspect. In their interview study on the perspective of children, their parents, and caregivers on the implementation of family-centred care, Coyne et al. (2015) confirm that agreements and role definitions are recommended before the start of therapy. Both unclear role allocations and a lack of information as well as unspoken expectations cause stress for families (Coyne, 2015).

At the same time, stress and excessive demands are channelled back to the clinic staff through complaints and dissatisfaction, which in turn can lead to dissatisfaction and frustration among clinical staff. The observed normative evaluation practices of clinic staff, which often categorise accompanying persons in a dualism of 'good, committed' and 'bad, lazy', can be understood as a strategy for dealing with their own frustrations. Particularly striking in this context was the devaluation by the clinic staff of accompanying persons with a high need for rest and recuperation, which was interpreted more as an expression of laziness and selfishness than of high stress. This raises the question of how these character traits might also relate to class, gender, or ethnicity-based stereotypes by healthcare providers (Mahabir et al., 2021).

Self-caregiver

AP were able to benefit from the exchange with other AP about the child's illness and problems in everyday life. This gave them the feeling that they were not all alone in this situation and tips and advice could be exchanged. In the interview study on participation in the children's rehabilitation programme by immigrant parents in Norway by Arfa et al. 2020, the exchange of experiences and socialising with other parents was also highlighted as a positive aspect. Observing other parents dealing with their challenges strengthened their perseverance (Arfa et al., 2022).

However, the exchange with the other accompanying persons was only possible to a limited extent, as childcare was not guaranteed by the clinic. The accompanying persons supported each other by organising childcare among themselves.

The lack of support in the day-to-day care of the children by the clinic staff during the rehabilitation stay places an additional burden on the shoulders of the accompanying persons. This sometimes makes it difficult for them to participate in their own activities as part of the APP. This presumably structural problem within the clinic can possibly be explained by the fact that APP are not yet structurally established in Germany, meaning that there are still no uniform agreements regarding the design and funding of such concepts. The key issues paper on AP adopted in 2022 and the associated piloting of such programmes could possibly change this. In an interview study by Coyne 2015, in which children, their parents and nurses were asked about their perspectives and expectations in the context of a family-centred treatment approach in Ireland, the support of parents by taking over 'basic care' (bathing, feeding, dressing, mobilising etc.) is justified by the fact that nurses lack the resources for this (Coyne, 2015). This can possibly also be applied to the current situation in the context of the APP. The clinic staff may be working at full capacity due to the implementation of the APP and the additional work that this entails, or they may be burdened with additional tasks and responsibilities in everyday clinical practice.

Clients of care

The interviews with the AP revealed that they reported a high level of stress and exhaustion at the beginning of their rehabilitation stay. The clinic staff is also aware of the high level of stress and the overwhelming state of the accompanying persons and that this has an influence on their participation in the accompanying persons programme.

The meta-analysis by Cousino et al. (2013) concludes that caregivers of children with chronic illness report significantly more 'general parenting stress' than caregivers of healthy children. Qualitative analyses of further 96 studies found in this context that greater parenting stress was associated with more parental responsibility, for example in relation to therapy management. The increased stress level of parents should be taken into account in future interventions (Cousino & Hazen, 2013).

There is room for interpretation here; the interviews were conducted when COVID-19 effects were still significant. German pandemic restrictions likely increased psychological stress from working and caring at home (Koerber et al., 2023). Vulnerable children with chronic illnesses also faced impacts on their well-being and their families (Warschburger et al., 2023).

Conflict of roles

Conflicts can be observed when too little attention is paid to the roles of *self-caregiver*. AP spend several weeks in the clinics and are intensively confronted with the relationship to their sick child, so that their own needs also need space. Their expectations of the clinic staff to recognise and support their needs conflict with the organisational conditions of the clinics in general and the concept of the AP in particular, which sees the AP in a secondary role. The demands on the AP are a priori closely linked to their role as *child-caregiver*; Goffman describes that role demands that are too overbearing lead to distancing from this role, as this prevents other aspects of the personality from coming to the fore (Goffman, 2013). This is where the role of *client in care* come into play, which the clinic setting and their tasks as 'learners' (Smith & Samuels, 2021a) also bring about.

Also the simultaneous care of the child by (clinical) experts and close (family) caregivers holds the potential for a conflict of competence, and AP may be subject to (in)direct criticism in this context.

Limitations

The results of the interview study on the concept of the APP were largely discussed with literature from the international context. It should be noted that although the international concepts are similar, they differ in various ways from the German APP, so that no direct comparison is possible.

Mental illness is not directly mentioned in the interviews with AP. This may have to do with the fact that not all of the accompanying persons with the highest level of stress or those with mental illnesses agreed to take part in an interview. The fact that they did not initiate this topic themselves could possibly be related to the fact that mental illnesses are still associated with a certain degree of shame.

Some of the interviews were conducted by the study nurse who, in addition to her work as a study assistant in the local rehabilitation clinics, also works as a movement therapist in one of the two study-clinics. In addition to the children, some of the accompanying persons interviewed also took part in the exercise therapy courses themselves. The active involvement of the study nurse in the everyday life of the clinic and in the APP could possibly have influenced the interview participants in their response behaviour with regard to social desirability. It is striking that the interviews conducted by the study nurses in particular were very short. This could indicate that the AP may have held back in the scope and depth of their explanations in the interviews due to bias on the part of the study nurse.

CONCLUSION

The interview study with AP and different professional groups of rehabilitation clinic staff clearly reveals the heterogeneous views and perceptions of the various actors. At the center of this there are the AP, which are confronted with different role requirements, namely that of *child-caregiver*, *self-caregiver* and *clients of care*. It is striking that the role of child-caregiver takes up a large amount of space, the role of self-caregiver can only be realised to a limited extent and the role of clients of care shows a great need that must be met.

The different tasks and expectations associated with these different roles present both the AP themselves and the rehabilitation-clinic staff with challenges that need to be overcome together. Both groups of actors should be aware of the multidimensional roles that emerge in clinical setting. Transparent information transfer and communication, clear role allocation and consideration of the individual needs and (health and social) requirements of the AP should be focused by planning and designing of APP. Active involvement and mutual exchange between accompanying persons and clinic staff should be at the forefront of this process.

ACKNOWLEDGEMENTS

The authors would like to thank all interviewees for their participation in this study. We would also like to thank the cooperating rehabilitation clinics for their participation in the study and the German Pension Insurance Rhineland-Palatinate for their support

COMPETING INTERESTS

The authors declare that they have no competing interest.

HUMAN ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The study protocol for this qualitative study was approved by the ethical review committee of the Charité - Universitaetsmedizin Berlin (reference EA2/297/21). All participants gave written informed consent to participate in the study.

FUNDING

EvaBePe is funded by the German Pension Insurance Rhineland-Palatinate (grant no. 423-01- 3310). The funding organisation had no influence on the conduct of the study, the collection, analysis and interpretation of the data, or on the preparation, review and approval of the manuscript.

The publication of the article is supported by the Open Access Publication Fund of Charité-Universitätsmedizin Berlin and the German Research Foundation (DFG).

LIST OF ABBREVIATIONS

AP = accompaying person
BR = Begin rehabilitation
ER = End of rehabilitation
CE = Clinical employees

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