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ORIGINAL ARTICLE

Who are relatives? Young adults, relatives and professionals' perceptions of relatives during the rehabilitation of young adults with a severe acquired brain injury

Mette Ryssel Bystrup[a,b], Lena Aadal[b], Hanne Pallesen[b], Kristian Larsen[c] and Anette L. Hindhede[c]

[a]Department of Culture and Learning, Aalborg University, Copenhagen SV, Denmark; [b]Department of Clinical Medicine, Hammel Neurorehabilitation Centre and University Research Clinic, Aarhus University, Hammel, Denmark; [c]The University Hospital Centre for Health Research (UCSF) & University of Copenhagen, Copenhagen, Denmark

ABSTRACT

Purpose: This paper explores the perception of "relatives" during the rehabilitation of young adults with severe acquired brain injury (SABI).

Methods: This longitudinal qualitative study followed eight young adults with a SABI from hospital discharge to a year and a half after discharge. The design encompassed professional records, interviews, and surveys, including a name generator list completed by the young adults and focus group interviews with both their families and professionals. We apply a sociological theoretical framework concerning friendship, and we employ social network analysis (SNA) methodology to capture, visualise, and analyse the young adults' significant social relations.

Results: Social relations engaged as relatives during rehabilitation are to a large extent determined by the perceptions of professionals and the parents of the young adult. These perceptions contain a limited number of social relations, with priority given to biological and juridical ties. This might reflect the reduced social support available for the young adult, who initially had a much larger social network.

Conclusion: The authors suggest a professional rethinking of who "relatives" are as well as considering these social ties as dynamic.

➤ IMPLICATIONS FOR REHABILITATION

- Rehabilitation professionals must be aware of and pay attention to differing perceptions that exist as to who qualifies as significant social relations in order to reconsider the practical implementation of relative involvement.
- The perception of who relatives are during the rehabilitation process should be reconsidered and extended to include who the young adult perceive as significant social relations.
- Relatives are not a fixed entity and should be considered dynamically throughout the rehabilitation process.
- Social relations of the young adult must to a larger extent be considered during rehabilitation to prevent social isolation in the long run.

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Engagement; rehabilitation; relatives; severe brain injury; social network

Introduction

A call for increased patient and family involvement is evident in Western countries, with public health care systems coming increasingly under financial pressure [1]. This is reflected in supranational policy statements and directives, such as the World Health Organization's call for a people-centred health service that adopts "the perspectives of individuals, families and communities" [1]. Family involvement is especially crucial in rehabilitation following severe acquired brain injury (SABI), leading to an extensive dependence on others because of physical, cognitive, social, and behavioral limitations [2].

Acquired brain injury (ABI) is a leading cause of chronic disability for individuals under 35 years of age [3]. According to Bakmann et al. [4], the age-illness combination makes young adults with SABI particularly vulnerable, raising issues of education, job, family, and social life. Across disabilities, the quality of young people's life depends on the maintenance of social participation and social relations [5]. People with SABI are at high risk of a significant decrease in friendships and social support, and to a large extent they lack opportunities to establish new social contacts and friends [6]. This increases their dependence on the family [7] taking on various supportive roles after an ABI [8]. For example, during rehabilitation, families constitute a valuable collaborator for professionals since they know the patient's life history [9]. Overall, such family engagement is considerable and related to both health outcomes and community integration for ABI survivors [10–13]. Family engagement in the rehabilitation of people who are critically ill is, according to Haines [14], an underutilised resource within the health care system, and there is currently little evidence to guide the engagement of families in such a process. In Danish political documents [9,15,16] we find a

CONTACT Mette Ryssel Bystrup metbys@rm.dk Department of Clinical Medicine, Hammel Neurorehabilitation Centre and University Research Clinic, RM, Aarhus University, Voldbyvej 15, DK-8450, Hammel, Denmark

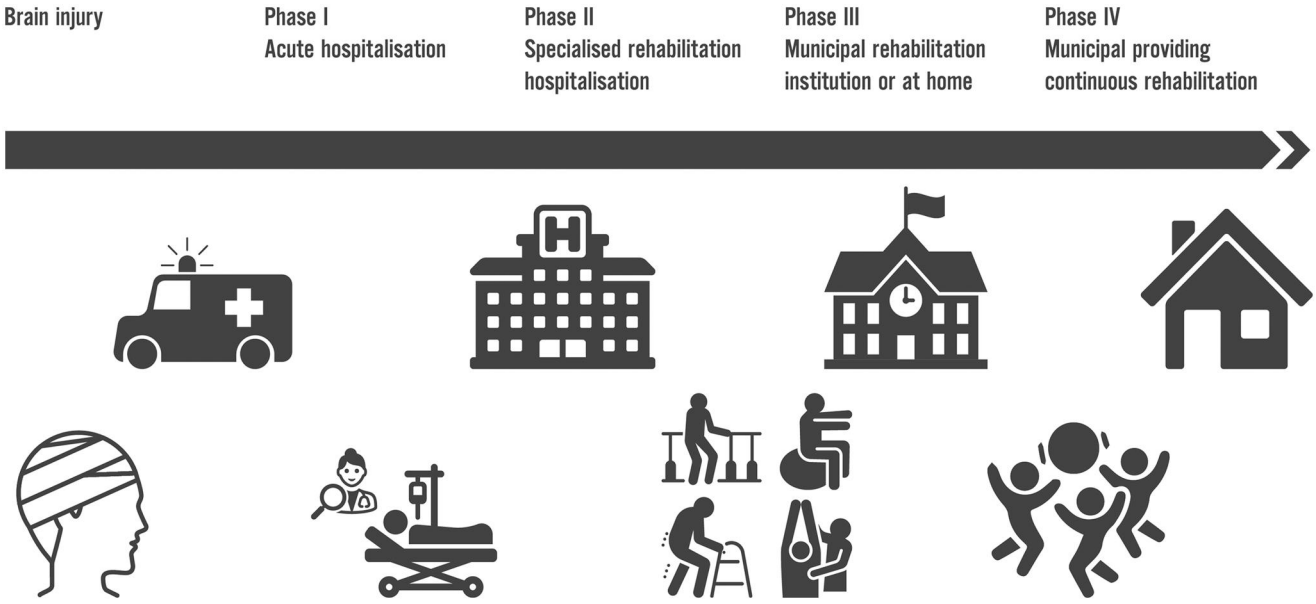

Figure 1. Rehabilitation phases after a brain injury, inspired by Danish Health Authority [21].

shared sense of obligation linked to the role of the family, even when the illness is chronic. These documents also indicate that the patients themselves are in charge of identifying who should be informed and involved. This is in line with the citizenship paradigm stressing autonomy in terms of rights and duties and self-determination [17]—in this context the right to decide where, how, and by whom support is given. According to Schipper et al. [17], however, there are different views between professional caregivers' and clients' understandings of what is considered a meaningful life. We hypothesise that the same differences are in play when it comes to opinions of who is to support the injured. According to Heaney and Israel [18], social support can be provided by many types of relations, such as platonic friends. To be sure, when the patient is not capable of designating their relatives (either because of their age or because of a lack of functional ability) or when conflicting issues appear, we enter a legal and ethical grey area [16,19,20]. To define who could constitute such support, the citizenship paradigm [17] directs our attention to the injured themselves and to their perceptions of significant others. We compare this to the perceptions of professionals. We therefore ask: *Who are perceived and engaged as "relatives" during rehabilitation? How does this relate to the young adults' own perceptions of significant social relations in their lives, both before and during rehabilitation?*

Setting description

In Denmark, treatment and rehabilitation following SABI is divided into four phases with changing responsibility and tasks between hospitals and municipalities. The rehabilitation trajectory of SABI patients address their complex needs and the majority receive all four phases; two in hospital and two in their own municipalities [21]. The first phase covers acute hospitalisation, whereas the second is highly specialised rehabilitation provided by two hospitals with national coverage. As the complexity of the patient's need decreases, they are transferred to a regional hospital or most often directly to rehabilitation provided by the municipal (Phase 3). This transfer could be to a municipal institution, a purchased provider, or home. Phase 4 is also provided by the municipal authority as it is responsible for patients' continuous bodily function development and maintenance (Figure 1)

Theoretical and methodological framework

The term "social network" is used here to refer to the social relations surrounding individuals. Dimensions of social relationships can be divided into structural and functional aspects. Structural characteristics contain facets such as the density, duration, dispersion, reciprocity, and homogeneity of a relationship. The functional aspects of relationships concern the purpose and nature of relationships, such as social support [22].

In order to explore social support being one of the functions of social relationships [18] that emerge when the ties are activated [23], we study structural characteristics and functional aspects of social relations throughout the rehabilitation trajectory. We draw on the sociological work of Spencer and Pahl [24] and Pahl and Spencer [25], who argue that relatives should be considered through a broader and renewed understanding. "Personal community" is an analytical tool used to capture all people that the young adult considers important. Both "family" and "friendships" are ideological, symbolic constructs often used in society and by professionals in rehabilitation. In reality, they argue, people have a much larger friendship pool, where the greatest support is not always defined by blood [25]. Rather, late modern society's personal communities are characterised by complexity, individualisation, and a variable mode of relating where physical distance is not important [24,26]. This breaks with traditional constructs based on the biological, legal, or normative definitions of community. Altogether, the personal community, made up of both given and chosen ties, constitutes a kind of social glue, providing continuity through shared values and interests. It also helps individuals to develop a sense of identity and belonging along with moral and normative dimensions (such as relying on and being there for each other), including in the event of a severe illness [24]. This encompasses not only manifest social support but also the imagined or perceived support providing a buffering effect.

In order to explore perceptions of who constitutes a relative, we consult the concept of "personal relations in the social mind"

Table 1. Overview of data material.

	Young adults		Family members		Professionals	
Time after hospital-isolation	6 Months	18 Months	6 Months	18 Months	Hospital	6 Months
Data sources	Surveys interviews	Surveys interviews	Focus group interviews	Focus group interviews	Professional records	Professional records Focus group interviews, residential institution
Number of (focus group) interviews	7	6	8	7	–	9
Number of interviewees	7	6	25	21	–	16
Length of interviews	20–60 min		60–160 min		30–90 min	

(PRISM) [25]. A person's PRISM reflects background variations, which we in this study relate to institutional embedding (professionals) and the life phase and societal groups they belong to (being a young person or being a parent). Hereby, the PRISMs coalesce into a cluster of roles amongst the three groups studied (the young adult, the relatives, and the professionals), with idealised and internalised models of behaviour, and, hence, perceptions of and expectations concerning relatives. Unlike models of family and friends, the personal community is not well established in the social mind [25], limiting the possibility of constructing these empirically through interviews. Instead, we combined theories and alternative empirical approaches to break with traditional perceptions in the social minds. Here, social network analysis (SNA) provides a unique entry point through which to study social network relations of the young adults and its dynamics over time in the years after an ABI.

Design

This study had a longitudinal and qualitative case study design, suitable for in-depth exploration of engagement and perceptions of social relations. It consisted of a methodological triangulation [27] with the following data sources: professional records (from the specialised rehabilitation hospital and from any residential institutions a patient attended), surveys, interviews and focus group interviews; various rehabilitation contexts (rehabilitation hospital, residential rehabilitation institutions, and/or care homes, the latter two referred to as residential institutions); various perspectives (the young adults, the relatives, and the professionals). Data were acquired over time, from before discharge to a year and a half after discharge. To create an overview of the data sources, see Table 1 below.

The period of hospitalisation lasted between 2 months and 12 months. This meant that survey questions on social relations before injury required recall from eight months to up to one and a half years, since the recall of social relations before the injury were constructed six months after discharge. The period of specialised rehabilitation hospitalisation and following institutionalisation lasted between 3 months and 17 months, hence constituting the time span of records collected.

Ethical considerations

This study was approved by the Danish Data Protection Agency (ID 1-16-02-552-15), and the data were handled according to its requirements. The study follows the principles of the Helsinki Declaration [28]. Written and verbal information was given to all participants by the first author before informed consent to participate was obtained. For young adults with expressive cognitive difficulties, a visual and reduced version was used. In the cases of two young adults unable to give informed consent, consent was obtained by proxy (in both cases the mother). Dual consent, from both the young adult and by proxy, was required in a total of three cases, either due to doubts about the young adult's comprehension and their ability to formulate clarifying questions or because they were younger than 18 and therefore had no legal right to give informed consent. Participants were all informed of the voluntary nature of their participation and the possibility of withdrawal at any time with no implications for future treatment or rehabilitation. The transcribed data have been anonymised, and pseudonyms are used in the reported findings.

Recruitment and participants

Eight young adults (aged 15–30 years old) with a SABI were included, each entering the study between December 2015 and March 2016. They had all had hospital stays longer than 28 days [29], and with expected needs of specialised and comprehensive rehabilitation and/or care needs after discharge. We strove for a broad representation amongst the young adults in terms of sex, age, ethnicity, functionality, and social class. In addition, the young adults represented various organisational and institutional framings (region, municipality, and rehabilitation institutions) and services after discharge (Table 2).

All patients were included in the study through a physical meeting assisted by a hospital professional from the hospital departments. In addition, the hospital department teams assisted by indicating to the first author whom they considered the "primary" relative. This relative then decided who should be invited to the focus group interview with the families (parents, siblings, girl/boyfriend).

The professionals recruited consisted of therapists (occupational, physio, and speech and language), pedagogues, social- and health care assistants, and social workers from the rehabilitation institution and municipal services. The number and position of the professionals were determined by those who responded to our invitation soliciting interviews with the professionals who worked most closely with the young adult.

All the data were conducted and analysed from an outside perspective by the first author (educational sociologist and PhD student). This was further qualified through enriching discussions with the co-authors, two of which have a sociological background and another two who are neurorehabilitation researchers and can provide an insider perspective. The first author was a female in her late thirties with a middle-class background and Danish nationality. Her "outside" position (e.g., she was not a medical professional, did not wear a uniform, and used non-medical language) reduced the signalising of institutional interest or rehabilitation purpose, inviting the participants to share their perceptions without a rehabilitation purpose of the encounter.

(Focus group) interviews

Semi-structured interview guides with open-ended questions constituted the framework for interviewing the young adults, their relatives, and the professionals in order to study the functional

Table 2. Sociodemographic profile, functionality, and organisational framing of the included participants.

Sociodemographic characteristics	$n = 8$
Sex	
Female	4
Male	4
Age at discharge	
Younger than 18	3
18 and older	5
Social class	
Middle class	2
Working class	4
Under class	2
Functionality	
Severity of brain injury (FIM score)	
18–49	5
50–99	2
100–126	1
Organisational framing	
Region (access to HS rehabilitation)	
Same region as HS rehabilitation	4
Other region than HS rehabilitation	4
Municipality	
Number of different municipalities	5
Setting/context after discharge	
Rehabilitation institution	4
Care home	1
Home	3
Service provision after discharge	
Municipal institution	5
Institution purchased by the municipality	3

aspects of social relations. The young adults were interviewed in their everyday environment 6 months and 18 months after discharge. They were asked questions concerning their social relations before the injury, during hospitalisation, and after discharge. The young adults had various degrees of cognitive and physiological impairment that affected their ability to recall and articulate their experiences and perceptions. This was addressed using e.g., visual support items and techniques [30–32]. The young adults were not interviewed with the rest of their family in order to give both young adults and families the space to talk freely.

Focus group interviews [33–34] with the families were conducted six months and 18 months after discharge. They took place in families' homes in order to allow for a freer dialogue compared to an institutional setting. The interview guide comprised broad questions with a loose structure, enabling space for interplay and negotiation of meaning-making between the family members (e.g., perceptions of the rehabilitation process, perceptions of and relations with relatives/professionals). Hereby, we gained observational knowledge of family dynamics used to validate the verbal expressions of the interviews in the construction of PRISMs.

Focus group interviews with the professionals were conducted six months after discharge and were guided by a semi-structured interview guide exploring the exchange and elaboration of various perspectives on handling of and working with the social relations of the young adult.

All interviews were audio-recorded and transcribed verbatim by the first author.

Surveys

In connection with the interviews, each young adult completed a survey, which included a name-generator list wherein they were asked to name who was significant to them (before the injury, six month, and 18 months after discharge), the nature of the relation (e.g., family, neighbour, professional) and frequency of contact. Inspiration was found in the SNA literature, e.g., Fischer [35] and Scott [36], including qualitative SNA approaches described by Alexander [37], Heath et al. [38], and Trotter [39].

Both the interview guides and surveys were developed by the first author in collaboration with the co-authors and with support from speech and language therapists from the hospital. All the surveys and interview guides were piloted on two cases and hereafter refined.

Professional records

Professional records enabled us to examine how professionals routinely think and act concerning relatives in a manner that is detached from self-presentation [40]. A sociological document review strategy inspired by Kropp [41] was used to create a chronology of the encounters between the professionals and relatives and to create an overview of the content of these encounters by registering certain information: date, institution, actors (e.g., parents, siblings, friends), form of presence (e.g., physical meeting, physical interaction, phone, mailing/SMS), and purpose of the encounter (e.g., information delivering, decision-making).

Data analysis

The young adults' significant social relations were qualitatively mapped as an ego-centric network from a bottom-up perspective and used as a concrete tool to study the structural aspects and dynamics of social relations [42]. The young adults constitute the ego(s) (a square-like figure), and the relations they mention are linked to constitute alters (placed in circles). The nature of the relations was indicated by different colours for each of the young adults (red for family, orange for friends and green for neighbours, etc.) [38]. The quality of a contact, based on the frequency of the contact between the ego and alter [39,43], was visualised by the thickness of the arrow. These network maps were compared (number of social relations, who they consisted of, and quality of the relations) over time to visualise changes. However, they were not compared between the cases, since the need of social relations varies between human beings.

The interview transcriptions and records were read and reread by the first author to familiarise with the data and gain a sense of the whole. Hereafter it was organised and coded using the computer software Nvivo [44] (Table 3).

The coding was inspired by thematic analysis as described by Terry et al. [45], starting with a broad initial coding of the records and interviews and steered by a curiosity about exploring social support in neurorehabilitation. Theoretical inspiration from Pahl and Spencer [24–25] and SNA was applied to the empirical data to construct the PRISMs of the three parties (professional, young adults, and relatives), hence the personal community of the young adults. This was done by a second coding with special attention to divergent considerations and perceptions of who should constitute core social relations of the young adults amongst the three parties (young adults, relatives, and professionals). The coding consisted of all social relations, their nature (e.g., family, friends, co-workers, girl/boyfriends), type of involvement (e.g., information delivered, professional initiated activities, non-professional activities, practical assistance, decision-making, participation in meetings), and attitude/perceptions (e.g., overstimulating, assisting).

Data collection and analysis occurred simultaneously. In practice, this entailed moving back and forth between theories and the construction and analysis of empirical material, as Tavory and

Table 3. Steps in the process of the thematic analysis.

Steps	Content
1) Familiarising with data	All the data material was listened to, transcribed, read and reread to gain a sense of the whole. The first author undertook the transcription
2) Generating initial codes	The data was transferred to Nvivo 11. Systematic and thorough creation of meaningful labels to specific segments relevant to explore various expressions of social support in neurorehabilitation
3) Constructing themes	Similarities in the initial codes were identified and a first version of salient patterning was constructed
4) Reviewing themes and consulting theories	Rereading the themes sharpened our attention to various perceptions in the data material of who constitute social support. In addition, a curiosity emerged of exploring who constitutes the social support. Theoretical inspiration was found in, e.g., Pahl and Spencer's concepts of personal community and PRISM as well as SNA. This founded the basis of a second coding
5) Defining themes	Refinement of initial themes took place, and new themes emerged. An interpretative orientation steered this definition and naming and initiated the writing of a fragmented analysis
6) Producing the final text	The fragmented analysis was converted to a coherent analytical text used illustratively, e.g., in the case exemplifications

Timmermans [46] suggested when describing an abductive approach.

Findings

The study participants had divergent perspectives on the designation and consideration of relatives throughout the young adults' rehabilitation. The young adults were all inpatients at acute hospitals before going on to one of the two specialised rehabilitation hospitals in Denmark. This period of hospitalisation lasted between two and a half months and one year and was a period characterised by unclarified juridical relations (guardianship). Subsequently, six of the eight young adults moved to a residential rehabilitation or care institution (typically located far from their pre-existing personal community) with attached health and pedagogical professionals. Two young adults returned home to their parents after hospitalisation, with professional rehabilitative assistance provided by the municipality. Eighteen months after hospitalisation, two further young adults had returned to their parents' homes, and one of these had just moved into his own apartment, albeit with 24-h professional support and located close to his parents. These rehabilitation courses frame the presentation of our findings below. First, the PRISMs of the professionals are categorised as belonging to a hospital or a residential institution/municipality. Second, the PRISMs of the young adults are categorised depending on whether they were demarcated by their closest relatives' perception or whether the young adult had identified a sense of belonging. Third, the PRISMs of the relatives are categorised as being defined by family rights, or as being the personal community of the young adult.

Table 4 provides an overview of the findings presented in the following, including the time where this PRISM was primarily observed/analysed. This might give the impression of a linear process/development of PRISMs in the specific rehabilitation phases, but in reality, this was a dynamic and circular process strongly related to e.g., the complexity of the ABI.

PRISMs of rehabilitation professionals

The PRISMs of rehabilitation professionals fall into two distinct categories: first, PRISMs of professionals from the specialised rehabilitation hospital, including medical doctors, therapists (occupational, physio- and speech and language therapists), neuro-psychologists, neuro-pedagogues, nurses, and social and health care assistants (referred to as assistants). Second, PRISMs of professionals from the residential institutions (therapists, neuro-pedagogues, pedagogues, neuro-psychologists and assistants) and municipalities (social workers and therapists), referred to as "other professionals."

Hospital professionals—too many relatives disturb the training of the physical body

In the hospital setting, the number of relatives considered by the professionals, based on the relatives mentioned in the interdisciplinary status, were two or three close biological ties (in all cases the mother, in most cases the (step)father, and in three cases siblings). Only in one case (a young adult aged 19) was a boyfriend designated a (primary) relative. Designated relatives were considered collaboration partners when discussing and deciding upon issues related to the well-being of the young adults and the relatives themselves, such as rehabilitation, everyday life of the young adult, and participation in activities. The extent of collaboration with the primary relatives varied: for patients under the age of 18, the mother (or parents) was co-hospitalised; for those over 18, the presence of the parents varied significantly based on the parents' life situation and other obligations. In the records generated by hospital professionals, ties emphasised by the young adults (friends, acquaintances from recreational activities etc.) were mentioned only sporadically (e.g., when visiting). These were very seldom referred to by name but were instead categorised by hospital professionals as, for example, "guests" or "former colleagues." The presence of non-primary ties was especially an issue of regulation. Professional arguments contained the need to regulate and limit the presence of the personal community in order to avoid overstimulation, and the need to direct their energy towards physical and cognitive training, which was considered the main purpose of rehabilitation. The professionals sought to regulate contact with non-primary ties not only when the young adult was in the hospital but also on weekends spent at home. For example, in the case of a young adult aged 19, the hospital assistant expressed: "There have been many friends visiting [at home], both Friday and Saturday (…) I showed the mother the checklist they have brought home with them where we recommended one visit of one friend once in a weekend. I tell the mother that I think it is too many visits because I don't think Christian is resting enough."

Other professionals (residential institutions and municipality)—"overtaking" primary relative(s) from the hospital

The PRISMs of the professionals following hospitalisation considered the primary biological relative(s) (sometimes also two, e.g., both parents) as their natural main collaborators. This unquestioned engagement sometimes implied the exclusion of other

Table 4. An overview of the findings of the article containing PRISMs, the rationale behind and primary time period where this has been identified.

	Professionals	
	Hospital professionals	Other professionals
PRISM	2–3 Biological ties. Other relations are regulated and confined	1–2 Biological or juridical ties are "overtaken" from the hospital. Provision of a substitutive social network
Rationale	Biomedical rationale—too many relatives disturb the training of the physical body	Availability/pragmatic approach—who is at hand and what do time and culture allow us to consider
Time period	Phase 2	Phases 3 and 4
	Young adults	
	Demarcation defined by relatives	Demarcation defined by social belonging
PRISM	A few selected social relations around the young adult	A larger network centred around the young adult/the family from before the injury
Rationale	Dependence on parents determines and reduces the social network	Dear ones from home, identification with others, or shared interests defines the social network
Time period	Phases 3 and 4	Phase 3
	Relatives	
	Demarcation defined by family rights	Demarcation defined by the personal community of the young adults
PRISM	Parents and siblings closing up in a small family unit	A larger group of people consisting of family, friends, and other social relations surrounds the young adult and support each other
Rationale	Gatekeeping from definers of having the rights, feeling sympathy or protection	Everybody is equal and all have access to the young adult
Time period	Phase 2	Phases 2, 3, and 4

biological and close relatives (e.g., a biological father divorced from the mother or a maternal aunt who was the designated contact person for the young adult before the injury) due to conflicts amongst these relatives.

In an interview with two municipal professionals (social workers with respectively 1½ and 22 years of self-reported experience working with people with ABI) on how they designated the primary relative of a young adult aged 22, they gave us this example: "it is very obvious from the beginning, because we already had communication with the mother at hospitalisation (…) Well, she is very much 'on,' yes, pro-active in the process. So, it is obvious that at any rate it is her we are to collaborate with, I think. We know that quite early on." Both professionals mention never having had contact with the father (the parents were divorced). This was regardless of the young adult's own perception of the strength of these particular ties. Exceptions to the biological mother (or parents) being first in line were made in the two cases of ethnic minority families, where the young adults' siblings were activated because of language barriers with the parents: "Then we rely on someone like a brother or a sister with better linguistic skills, so we can communicate this way." The professionals' understanding of collaboration with the parents reinforced the independence of the young adult. This entailed a cutting of the strong ties between the young adult and their parents in the hospital, as expressed in an interview with one of the professionals (a pedagogue with 9 years of experience) concerning a young adult aged 17: "They [the parents] have lived there [at the hospital], they have slept there in turns and been there 24 h a day. And then they come here [residential institution], our task is to do the opposite. Now, we are to phase out mother." Collaboration was generally limited to handing over information to the mother (or parents), practical issues, deciding on the next step in the rehabilitation process, and resolving conflicts with the young adult.

The young adults' larger family networks (e.g., siblings, other parent) were weakly represented in the PRISMs of these professionals. The rest of the young adults' personal communities (friends, schoolmates, virtual acquaintances, etc.) were more or less absent, as expressed by a residential rehabilitation professional (a pedagogue with 4½ years of experience) when asked about his interaction with the friends of the young adult aged 19: "No, with his *friends*? [sounds surprised] Not at all, no no no." This was despite the fact that the young adults were by this point closer to returning home than remaining in hospital.

We see, thus, that despite the limited interaction between the professionals and the young adults' larger personal community, the PRISMs of the professionals remained a perception of who constituted preferable relations for the young adult. Their PRISMs were also framed by time and money available and the culture of the institutions the professionals represented. This is illustrated in an interview with a professional at a rehabilitation institution working with Christian age 19:

> Interviewer: What about the family surrounding the young adult? How do you consider them in your work?
>
> Professional: They are offered a session with a psychologist here in the house [institution]. Or, now I need to be careful of what I say, because this is of course a matter of kroner and øre [money].

Also, the professionals' PRISMs (especially at the residential institutions) involved providing a substitute social network of other disabled individuals. This was the case in Phases 3 and 4.

PRISMs of the young adults

The personal communities of the young adults changed in size, intensity, and reciprocity throughout their rehabilitation courses from before injury to 6 and 18 months after hospitalisation. Overall, the nearest family relations remained consistent, the total number and intensity of other family relations dropped, and relations with friends and classmates decreased. The latter was explained as changes in interests, lack of expression opportunities, and lack of common interaction spheres (e.g., school, football)

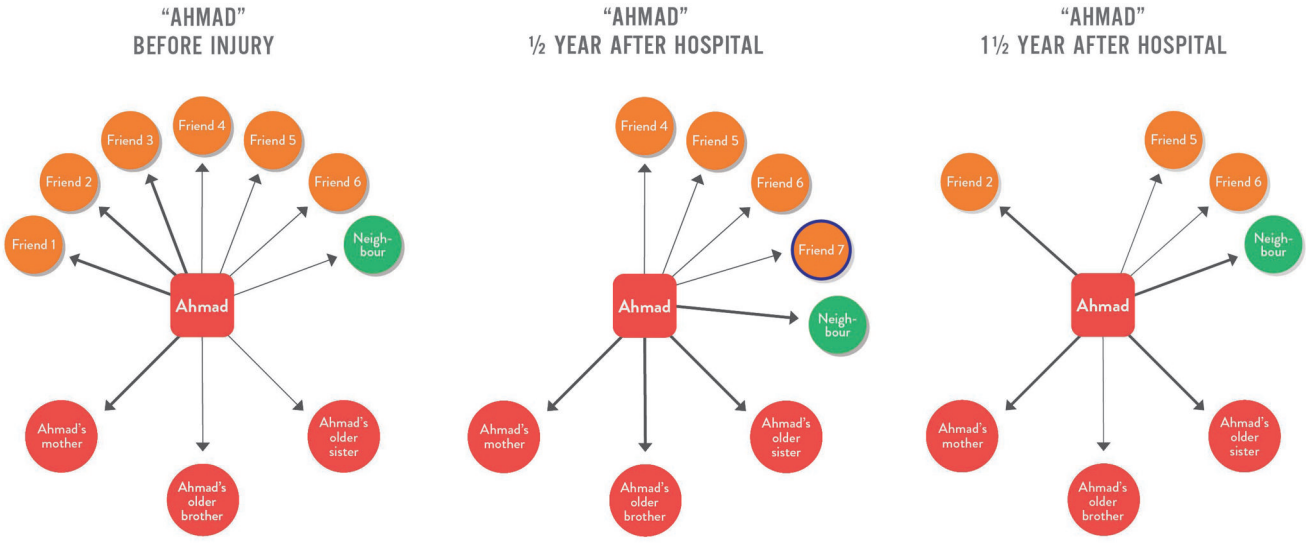

Figure 2. Ahmad's personal community.

framing the natural course of interactions. At the same time, these relations moved on in their lives. This influenced the PRISMs of the young adults, who now felt different and had different interests from their peers; for example, a girl aged 15 said, "I probably feel a little different (…) Just think it isn't healthy to drink (…)." When asked about boys and boyfriends, she said, "It is on standby, [now] it is exercising, exercising and exercising." An example of such a reduction in the size and strength of relations with friends and classmates (orange circles) and a strengthening of a few family ties is presented in the case of Ahmad, aged 17 (Figure 2):

While most of the personal communities of the young adults narrowed like Ahmad's, another young adult's personal community expanded through the activation of (new) virtual social relationships with peers with common interests, such as music, stand-up comedy, and dating.

Demarcation defined by the relatives—dependence of support from parents determines and delimits relations

Rehabilitation required young adults to be separated physically from their personal communities for a long time (in some cases permanently). This separation, combined with reduced functionality, often meant that the participant's mother served as a gatekeeper for the young adult's (re)connection with their social relations (e.g., opening up their home for friends and former colleagues to visit the young adults at the hospital or on weekends). Moreover, such connections often required parents to help facilitate the encounter between the two parties. In fact, some parents disapproved of other relations, and in some cases, this made it harder for the young adults to maintain social contact. An example was Smilla, aged 17, who spent considerable time engaged with virtual acquaintances (her substantial communicative disabilities only allowed her to give short answers):

> Interviewer: When you say that you have got new friends after the incident, where do you know them from?
>
> Smilla: The Internet.
>
> Interviewer: Yes, where on the Internet?
>
> Smilla: Tinder.
>
> Interviewer: And Tinder is a place to find a boyfriend or something?
>
> Smilla: Yes.
>
> Interviewer: And then you meet on Tinder but also in reality?
>
> Smilla: Yes.

However, Smilla's parents disapproved of these relationships: "Tinder is a terrible thing (…) it easily gets very sleazy. Ehm, from both parts you could say. They don't want shit other than … Well, sometimes they have markedly said that they want a virgin and then we would like to try one in a wheelchair (…) it would be good if Smilla could stop that and meet a real person." In general, the strength and quality of the network ties of the young disabled depended, to a great extent, on the support of the parent(s) (their primary biological relatives), which reflected their PRISMs. This was especially the case at the hospital (Phase 2), where the functionality of the young adult was the most reduced; this was also the period when the parents was the most around the young adult due to co-hospitalisation and the most intensive rehabilitation period.

Demarcation defined by social belonging—identification with others as a marker

In the young adults' PRISMs, this separation from the personal community while institutionalised was experienced as a discrepancy in their natural social sense of belonging. This experience consumed a great deal of energy and was an ongoing topic for the young adults (both 6 months and 18 months after hospitalisation). It was expressed in a number of ways, and related to e.g., homesickness, a lack of motivation for rehabilitation, a desire to escape, and multiple attempts to stay home longer on weekends. In the words of one participant, aged 19: "It is too far away from home. I think that is the reason that I don't bother anymore. My interest in this [rehabilitation] is just lost (…) I miss my friends a lot and things like that [tears in his eyes and a tearful voice]. All my dear ones I want to go home to." The institutional settings did provide participants with social interaction with others, with the common denominator that these other individuals had brain injuries and were, in some cases, young adults. This did not seem to be effective in developing a stronger mode of relating, since during name generation none of the young adults mentioned any of the other residents as a social relation, nor did they refer to them in the interviews as friends but merely as people they currently spent time with. This was expressed as difficulties in

Figure 3. Christian's personal community.

identifying with the other young adults due to variations in age, level of disability, ethnicity, interests, etc. For example, one of the young adults aged 17 with an ethnic minority background described his wish for relatable peers at the rehabilitation institution: "Come from a foreign family, played a lot of football and being good at football, having had the same interest as I had." Social belonging as a marker of demarcation was especially present in the empirical material in Phase 3 for young adults at residential rehabilitation institutions where the young adults were now often far away from home; together with the hospitalisation, this had lasted for a long period of time. At the residential rehabilitation institutions, with no co-hospitalised parents and with improved functionality, the young adults gained space for reoccupation with social life aspects.

PRISMs of the relatives

Overall, the relatives' PRISMs concerning who should be activated in the life of the young adults during hospitalisation, as well as during the subsequent period, can be defined according to juridical rights and biological ties or based on the personal community of the young adult. These two variations of demarcation, defined by either the relatives' perception or the personal community of the young adult, had a significant impact on the size and quality of the network over time.

Demarcation defined by family rights—gatekeeping from definers of having the right, sympathy, and/or protection

The biological and juridical ties constituting the PRISMs of the relatives, and which defined the activation of other relatives, entailed a primary focus on biological ties (and a few non-biological ties) and a hierarchy of who had the right to be engaged with the young adult and to what extent. This generally led to increased closeness amongst the few activated family members, but it also deactivated a large part of the young adult's personal community, which was not reactivated in the long term. In some cases, this aligned with professionals' directions to avoid overstimulation. In other cases, it was justified as a way of protecting others from the "scary" sight of the young adult (e.g., "They shouldn't see her in the beginning, because that's a picture they will never forget") or as a way to preserve the privacy of the close family (e.g., "[Father] and I both agreed on our need for silence"). In other cases, the young adult had a very limited personal community to activate. Mothers typically took on the strongest gatekeeping roles, based generally on the mother's own perceptions of deservedness, sympathy or claim to juridical rights, e.g., the mother of a young woman aged 27 who suffered a SABI in a traffic accident with her boyfriend: "he [boyfriend of the young adult] cannot first half kill her and then expect it [visiting her] to be okay afterwards." This PRISM was especially identified at the hospital (Phase 2), where the patients and their families were still in a relatively new situation with many ambiguities—for example, concerning guardianship—and where the exhaustion of the parents was not yet so present.

Demarcation defined by the personal community of the young adults—everybody being equal and all having access to the young

In other families, the young adults' personal network was more influential in defining access to their lives. This activation of a personal community entailed a breaking down of the hierarchy amongst the members (nobody having more right to the young adult than others), e.g., as observed amongst the ethnic minority families in this study. This meant opening up to a larger network and more relations providing support over time. In some cases, these personal communities were characterised by social cohesion (also evident for the family and not only the young adult) that predated the injury. Examples from the data of this study are religious groups or small communities characterised by a culture that binds them together and creates a community that is there for each other. This PRISM was identified in Phases 2, 3, and 4.

Case exemplification of PRISMs

In this section, two illustrative cases take their starting point in the PRISMs of the relatives. Agnes represents a demarcation defined by family rights who ended up with a very limited social network, and Christian illustrates a demarcation defined by the personal community of young adults, resulting in the maintenance of a relatively large part of his personal community from before the injury. Starting with the relatives' PRISMs in the case examples offer the most thorough longitudinal perspective, including the long-term consequences of the young adults' social networks.

Case 1

Agnes, 27, is an example of a young adult with reduced functionality preventing her from pointing out significant social relations in her life. Her mother and her mother's husband were designated as Agnes' primary relatives by professionals due to their biological ties. This was despite the limited contact between

Agnes and her family before the injury, as disclosed in the records: "[Agnes] has the past half a year before the injury not seen her family much and has probably lived with her boyfriend, who the family dissociates themselves from." Agnes' maternal aunt was identified by the professionals as an important social relation in her life. Notably, neither Agnes' boyfriend nor her two children were considered as relatives. During hospitalisation, the mother continuously tried to prevent the boyfriend from visiting. However, with juridical support, this was overruled by the professionals, as noted by an assistant in the records: "The family has not wanted the boyfriend to come visit while hospitalised, but after discussing the dilemma with a jurist, it is clarified that the family can't deny the boyfriend visiting." This changed at the care home, where Agnes' mother now had guardianship and was supported by the professionals in restricting who was involved in the life of Agnes, as explicated in the records by the manager (nurse): "Dear all. It is extremely important we adhere more strictly to confidentiality. All information concerning treatment—both medical care and others, must solely be given to [Agnes'] mother. NOT to [Agnes'] other relatives, also not the maternal aunt. If the maternal aunt asks about any of these things, you should refer her to me [nurse], [works manager] or [mother]." Eighteen months after hospitalisation, Agnes was left with a very limited social network. This was expressed as: "It is strictly speaking only [stepfather] and me [mother] and my three children [Agnes' siblings] visiting Agnes now. Nobody from my family visits her."

Case 2

Christian, age 19, is an example of a young adult managing to maintain a large part of his personal community throughout the rehabilitation process as well as upon his return home (Figure 3).

These relations originated from the small community in which his family had lived for generations, who immediately showed up in large numbers and provided support when he was hospitalised. His father described how this made him change his perception of who was entitled to be close to Christian: "Then, I withdrew and made space. So, the inner circle, which his mother, me, and his siblings were in, we needed to withdraw to the outer circle, so we then only had one large outer circle on equal footing. We all wanted the best for him, so, in that sense, nobody was preferential." The family expressed their gratitude for the group of friends; as his sister said, "They understood me. We were all in this together." This gratitude also encompassed perceived support: "I [mother] am 100% sure that if something happened, they would all be there again." The professionals at the rehabilitation hospital, on the other hand, considered only Christian's parents as his primary relations. They expressed concern that Christian would be overstimulated by the many relatives and therefore regulated visitors. This was expressed by a therapist in the record as: "Visitors are allowed in the time span from 2 pm to 4 pm and thereafter it is only the closest relatives who can be around Christian." This regulation was also in effect when Christian was home on weekends. At the residential rehabilitation institution, the professional (a pedagogue with four years of experience) considered the mother as the only relative and did not interact with the larger personal community: "They [friends] have been here to pick him up. I haven't seen any of them." Despite the long hospitalisation and rehabilitation (over a year) as well as his reduced functionality, Christian was still part of the group of friends upon his return home.

Discussion

This study shows that the social relations who were activated in rehabilitation were steered by the PRISMs of the professionals. These PRISMs contained a limited number of social relations and prioritised biological and juridical ties. This might be linked to a public ideology of the loving family, overlooking the negative impact on one's life if this relationship is characterised by mistrust, hassle, criticism, or domination [18]. It is also critical to acknowledge that family caregivers of patients with a SABI often find it a heavy burden to care for their loved one. This burden is reinforced by the severity and nature of the ABI [47,48]. The young adults themselves, in contrast, had a much larger personal community in which chosen ties also played a significant role in their lives both before and during rehabilitation. In between were the relatives' PRISMs, which were impacted by the authority of the health care system while themselves impacting the social ties of the young adults through gatekeeping. In this way, professionals' and relatives' PRISMs presumably may be linked to the reduction and weakening of the young adult's social network in the long run, ultimately shaping the social support available to them. Obviously, this weakening of ties also has a connection to the severity of the ABI, and hence to the physical and cognitive limitations of the young adult, impacting the interaction possibilities and thus also the sharing of activities and interests.

Discrepancy in PRISMs

The discrepancy between PRISMs (cf. Table 3) might also be explained historically: It is deeply rooted in hospital practices that imply that patients' healing bodies must be supported by rest, sleep, and quiet surroundings and should not be disturbed [49]. These traditions might still be reflected in the professionals' (and presumably also internalised in the relatives') PRISMs, in which a clear hierarchy gives the professionals the notion that they know what is best for the patient, with the patient expected to follow these guidelines. The discrepancy between institutional practices and the young adults' perception of relatives is also connected to temporary fictive kin [25], a substitute social network. Professionals may consider the other disabled individuals in the rehabilitation institutions to serve this role, though the young adults themselves generally do not consider them to be social relations. Such a provision of temporary fictive kin might be based on an outdated perception of relations being place-based and may thereby overlook the complexity of today's personal communities, which contain a more hidden kind of solidarity [24].

Discrepancy in PRISMs amongst health professionals in hospital and other institutions

The findings show that in hospital settings, as compared to residential (rehabilitation) institutions, social relations (especially parents) were more likely to be considered not only as practical collaboration partners but also as sustainable elements in the life of the young adult. This was somewhat surprising, as hospitals are dominated by a biomedical framing with a strong focus on enhancing the physical (and not the social) body [49–50]. In addition, young adults at rehabilitation institutions were closer, timewise, to potentially returning to everyday life and in some cases also to returning to their home community. To explain this surprising finding, we highlight the PRISMs of the hospital professionals framed by institutional regulations (e.g., possibility for co-hospitalisation), jurisdictions (e.g., compensating for a parent's loss of earnings while co-hospitalised, while the young adults was

hospitalised), and access to the latest knowledge on ABI (most available at hospitals with affiliated research units), stressing the importance of actively engaging the relatives of a patient in order to enhance reintegration into the community and their life satisfaction [51].

Consolidating PRISMs

Constructing the PRISMs of the professionals, relatives, and young adults is based on institutional embedding (professionals) and life phase and societal group belongings (being a young person or being a parent). We find it reasonable to assume that the PRISMs of the professionals were to a certain extent shaped by their perceptions of the state, which is a well-founded collective illusion existing inside us all (through mental categorisations and schemes of perception) and with real effects [52]. This collective illusion is acquired through, for example, educational socialisation to the welfare state profession as well as the institutional rehabilitation setting with its overall ICF principles for rehabilitation [53]. Based on this argument, we find it reasonable to cluster the PRISMs of, respectively, the rehabilitation professionals in the residential rehabilitation institution and the professionals at the hospital. This is due to the nuances of professionals representing different social positions, different institutions, and different practices regulated by different legal requirements. It could be advantageous to unfold such variations in future studies to strengthen cogency of constructed PRISMs. We find it reasonable to assume that the PRISMs of the professionals have had a strong indirect influence on the PRISMs of the relatives (and young adults), since the institutional framing gives power to traditions where professionals take on an expert role to be followed by the patients and relatives and provides them with the power to define the agenda.

Challenges and limitations of the study

Methodological challenges, errors, and bias are linked to the young adults' recalling of social relations and constructing the personal communities as addressed by, e.g., Almquist [54]. Examples are memory loss, which expectedly might be reinforced by an ABI, together with fatigue, cognitive challenges, etc. The gaps and silences that the cognitive disabilities entailed in, e.g., the constructed personal communities were accommodated by combining them with other data sources, such as interviews, for elaboration, contextualisation, and verification. We consider participants' expressions and statements (including those of the young adults) as their subjective perspective, which has value in itself in combination with an interpretation and reflection of validation.

The results in this study have been gathered from a relatively small number of participants and in a local Danish context constituting specific requirements. As a result, no claim is made of exhaustiveness or transferability to other contexts. In addition, as middle-class researchers who have not been in the shoes of someone affected by ABI, there are innate limitations to our grasp of the perceptions studied in this paper. However, preparational work containing of theoretical and practical knowledge acquisition contributed to the mental exercise [55] at play when entering into the various perspectives.

Since no survey has, to our knowledge, been developed for this target group, and accommodating the focus/aim of this study, the survey was developed by the first author. The survey has not been validated, raising questions concerning validity and reliability. But the close collaboration with the co-authors concerning the development, the inspiration found in SNA literature, and the testing on two families and following adjustments are attempts made to mitigate concerns. Empirical data collection was pragmatic and flexible, accounting for the vulnerability and instability of this group of patients as well as for their many different rehabilitation courses, resulting in a heterogeneous dataset. An example is the interviews with the professionals, which ranged from one-on-one interviews to a focus group with seven professionals; the professionals' time available to participate in the interviews also ranged from 30 to 90 min.

Inclusion in the study—an unintended reproduction

The inclusion of relatives in the study leads to gaps and silences in the achieved networks. The inclusion *via* a professional and *via* the nearest relative might have led to a reproduction of PRISMs, as their perceptions steered who should be appointed and hence may have reduced the number of relatives. This dynamic was not visible to the first author until the writing of this article. In addition, when the closest relatives were in conflict, no intensive attempts were made to include opposing parties. One justification for this cautious approach is that family conflict would risk the family's withdrawal from the study. However, in order to expand the group of individuals associated with each young adult, the first author engaged in dialogue with each mother (gatekeeper) in order to include siblings (in those cases where these were not mentioned by the mother) and boy/girlfriends of the young adults. Further, directing our attention to the perceptions of the injured themselves—including their diminished capacity, which might challenge their ability to involve people—includes dilemmas that would be relevant to further inquiries.

Conclusion

This study highlights the disconnect in the perceptions of who constitutes a relative to the young adults with a SABI. We found that being designated as a relative and being actively engaged is to a large extent based on the professionals' and closest relatives' perceptions of what constitutes a relative. Taking a limited view of who a relative can be could be linked to the reduction and weakening of the young adult's social network. Our study paves the way for a broader perspective on the engagement of relatives in rehabilitation. We hereby suggest professionals reconsider their perceptions of relatives as primarily being the closest biological and juridical ties, a notion that can be replaced with an awareness of the patients' larger personal community. In addition, we propose a dynamic perception of the concept and a longer perspective on the engagement of relatives. Such a perspective would take into consideration the possible support that a larger social network can provide both during various rehabilitation phases and when (re-)establishing everyday life. Thus, we challenge rehabilitation models and interventions that are directed at the families [11,51] and that do not consider a larger social network or the dynamics hereof throughout the rehabilitation trajectory.

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ORCID

Mette Ryssel Bystrup http://orcid.org/0000-0001-9402-9522
Hanne Pallesen http://orcid.org/0000-0001-6010-2306
Kristian Larsen http://orcid.org/0000-0001-6835-0814
Anette L. Hindhede http://orcid.org/0000-0002-0658-4858

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