**Family role in in-patient rehabilitation: a comparison of England and Turkey**

**Abstract (198 words)**

Purpose: This article compares family role in in-patient rehabilitation in Turkey and England.

Background: The literature predominantly assumes family presence in rehabilitation as positive, because it draws upon Western cases, where care is delivered fully by professionals, and patients may feel isolated during hospital stays. Analysis of other contexts provide a more nuanced view.

Method: This qualitative research included in-depth interviews (Turkey: 42, England: 18) with people with disabilities (n=39), their families (n=8) and (non-)medical staff (n=13); hospital ethnography (Turkey), focus groups (England: 3 groups involving 4 doctors, 5 nurses, 6 therapists), and participant-observation (England: 5 families). Thematic analysis highlights experiences of people with disabilities of family involvement across different contexts.

Results: Patients often experience family presence as positive. Yet, intense family involvement, as in Turkey, may imply loss of privacy and individuality. In England, however patients essentially experience family involvement as support and worry about losing it. The nature of participation determines whether families are experienced as enabling or disabling. Less regulated rehabilitation environments where families initiate spontaneous intra-hospital socialising can induce positive experiences.

Conclusion: Families need to be integrated in rehabilitation so as to support social interaction, but still allow people with disabilities to remain independent.

**Keywords**

Family, disability, in-patient rehabilitation, England, Turkey

**Article Category**

Research paper

**Word count**

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**Introduction**

The literature on family role in rehabilitation predominantly assumes family presence as positive, because it draws upon Western cases, where professionals deliver care and patients may feel isolated during long hospital stays. Analysis of other contexts provides a more nuanced view. This paper examines experiences of people with disabilities with family involvement in in-patient rehabilitation. It compares the family role in in-patient rehabilitation in two settings—Turkey and England—which were chosen for two reasons. First, they represent two distinct examples: Turkey’s health-care system assumes that families stay with patients in hospital and take on multiple responsibilities, from providing medication to hygiene. In England, families visit, but do not stay in hospital. Although relatives provide support, the National Health Service (NHS) assumes that hospitals attend to patients’ needs. This provides fruitful ground to analyse and compare experiences of people with disabilities of family involvement in in-patient rehabilitation. Second, the choice of settings also derives from the researchers’ backgrounds. One author is British; two are Turkish. The authors have conducted fieldwork in their respective countries and collaborated for many years, facilitating deep understanding of these contexts.

Our focus on family in in-patient rehabilitation fills an important gap in the relevant literature in disability studies, rehabilitation sciences, medical anthropology, and sociology. A literature review makes this gap apparent in four ways: First, even though there exists much research on rehabilitation and disability [e.g., 1,2], scholarly work on family often focuses on disabled children [3,4] or disabled adults’ parenting abilities [ 5]. Second, the literature on disability and the family emphasises the experience of family members as care-providers [e.g., 6,7], rather than that of the person with disabilities [exceptions include 8,9].

Third, English-language literature on rehabilitation and family lacks nuanced perspectives highlighting cultural differences. It concentrates on Western experiences and sees increased family involvement as positive [10-12], because it prepares families for out-patient rehabilitation [12]; both patients and families appreciate such involvement [13]; and families promote adherence to rehabilitation programmes [10]. Emphasising the concept of family-centred care [3,11], this literature highlights families’ needs and potential support for them, such as training [14], information-sharing [15], and families’ experiences during rehabilitation [16-18]. Three papers from outside rehabilitation sciences stress contemporary structural changes and states’ cost-cutting efforts to explain increased family involvement [18-20]. Specifically, Allen [20] concentrates on these changes’ micro-scale impact and points to tensions in nurse-family relationships. Daudji et al. [21] and Shikako-Thomas et al. [22] critically discuss family role, yet focus on disabled children in the Western context. The single critical paper on family involvement from disabled adolescents’ perspectives concerns Greece [9], where, similar to Turkey, the assumption of family as the best care-provider results in overprotection and overdependence. Finally, our review of Turkish literature on family and rehabilitation resulted in only seven papers, all concentrating on families’ coping mechanisms and needs as caregivers at home.

**Disability and rehabilitation theory**

This paper draws upon disability and rehabilitation theories. An adequate account of disability has to consider lived experiences of pain and limitation, psychological dimensions of identity-formation and family relations, and wider structural contexts of social barriers and stigmatization. For example, families’ construction of disability and rehabilitation influence newly impaired persons’ experiences. Inaccessible environments materially affect possibilities for people with disabilities. A critical realist account, with its laminated approach to social realities, is most useful, because it investigates the interplay of medical, psychological, and social-structural aspects [23].

Because social-sciences and humanities scholars in disability studies refrain from discussing rehabilitation, which they conceive as unwanted intrusion and form of oppression [24], rehabilitation theories are produced predominantly by rehabilitation scientists and health professionals [25-27]. Existing theory highlights the dominant ideology of normality in rehabilitation [25,27], criticizing its inherent imperative to fit people back in [26]. Solvang et al. [28] apply sociological theories for a comprehensive framework for rehabilitation services and analyse how individuals with disabilities, professionals, and governmental authorities act on micro-, meso- and macro-levels. Sturkenboom et al. [29] highlight how cross-cultural variety informs understandings of independence, care, and family. Our paper also indicates the importance of rehabilitation’s socio-cultural context [9,21,29].

**Contextual background: health-care and family**

As “foundation” of society [30, p.371], family constitutes a cornerstone of Turkey’s welfare regime. According to Esping-Andersen [31], welfare regimes include social-democrat versions in Northern Europe, liberal versions in the Anglo-Saxon world, and conservative ones in Germany and France. In the subsequent literature, Turkey—along with Greece, Portugal, Italy, and Spain—presents a Southern European Model [32,33], which emphasises family and household structures [34]. Yılmaz [30, p.371] states that the Turkish welfare state is dependent on the family as “a citadel of defence” for the individual. Hence, in health-care care-related state functions are partly assigned to family [30, p.374]. Thus, prevalent gender roles render women “invisible workers of the welfare state” [35 in 30, p.374]. Today, emphasis on family is even more apparent, as it forms part of the incumbent Justice and Development Party’s conservative and neoliberal mentality [30, p.377].

In England, whose welfare regime Esping-Andersen [31] associates with an Anglo-Saxon liberal model and the inclination to “minimize the state, to individualize the risks and to promote market solutions” [36, p.74-75], the labour movement has historically influenced social policy. In contrast to other Anglo-Saxon examples—i.e., the USA —it facilitated the rise of a more comprehensive and collectivist welfare state [36, p.75]. Yılmaz [37, p.59] asserts that, despite its recent transformations, the NHS has generally decommodified health-care services, resulting in family’s diminished responsibility in welfare and health service delivery. Although there is increasing emphasis on family role and family-centred care in Britain [8,20], England and Turkey continue to represent two different ends of the spectrum.

**Methodology**

***Positioning the researchers***

All three researchers are sociologists working in disability studies and, more recently, social experiences of physical rehabilitation. The British researcher, having a spinal cord injury, has personally experienced in-patient rehabilitation in UK. The remaining two are non-disabled scholars based in Turkey and have had close contact with its disability communities since 2009; one author conducted one-year-long fieldwork in a British rehabilitation hospital. All three have collaborated for the past decade; two conducted fieldwork across diverse regions. The British author has worked in global public health.

***Fieldwork***

The Turkish fieldwork was conducted in one of the country’s main rehabilitation hospitals in 2013, as part of a larger project exploring social constructions of disability during in-patient rehabilitation and how people with disabilities experienced these constructions. This larger study illustrated three significant issues: discourses surrounding the concept of “walking” in rehabilitation, rehabilitation technology’s role in the reproduction of bodily normality, and the family’s role in in-patient rehabilitation [23,38,39]. Ethical consent was granted by (deleted) University’s Ethics Committee and the Secretary General of the Turkish Association of Public Hospitals. Ethnography [40] was the chosen method, since participation in everyday life in the hospital facilitates discovering factors that usually remain unconsidered [39]. Here, ethnography—participant-observation, informal conversations, and socialising with families and patients—allowed incorporating family role and the hospital setting’s specificities into the discussion. The fieldwork lasted over summer and fall of 2013. We visited the hospital 3-4 times/week during summer and twice a week in fall. 42 in-depth interviews were conducted with 7 doctors, 2 nurses, 2 physiotherapists, 2 non-medical personnel, and 20 people with disabilities in the hospital, as well as 9 former patients. Interviewees with disabilities were adults older than 20 years of age, injured in traffic accidents, shootings, domestic violence incidents, or falls from height. Most patients stayed in hospital for 2-3 months. A consultant assisted with initial patient contacts; we eventually met the participants in their rooms, the hospital café, the garden, or the courtyard. Researchers maintained a fieldwork diary as integral part of the ethnographic data collection.

Fieldwork in England was conducted in a specialist rehabilitation hospital from October 2016 to February 2017. The time gap between the two fieldwork studies resulted from the researchers’ interest in family role in in-patient rehabilitation emerging in light of the findings of the earlier fieldwork in Turkey. Subsequently, European Commission funding facilitated comparative analysis with England. Ethics approval was obtained from the NHS Health Research Authority. Fieldwork comprised in-depth interviews, focus-group discussions and participant-observation. Patient participants were drawn from two different wards, amputations and neurological rehabilitation services. Interviewees included 10 patients (6 amputees, 4 from neurological services), and 8 family members (3 amputees, 5 from neurological services). Patient ages ranged from 40 to 81, the majority being in their 70s. Three focus-group discussions were conducted, with doctors (n=4), nurses (n=5), and physio- and occupational therapists (n=6), each lasting around 90 minutes. Participant-observation was undertaken with 5 families visiting patients (2 amputees, 3 in neurological services). In-depth interviews in both settings ranged from 7 minutes to 2 hours, depending on interviewees’ energy and willingness to interact. Most lasted about one hour. A staff member initiated first contact with participants, then the researcher met patients/families and made appointments for interviews. Initially the recruitment process proceeded slowly. Once interviewed patients shared their experiences, especially in the amputee service, where patients socialise more, we managed to recruit more patients.

In both settings, the sample size was determined by a saturation point after which recruiting more participants would not result in additional information. All interviewees were patients with the mental capacity to consent and converse. Patients have been anonymised, Turkish patient as TP, English patients as P; Turkish doctors as TD, and non-medical personnel (one social worker, one telephone operator) as TNMP; English family members as F, with added letters when quoting different family members of the same patient.

All interviews were tape-recorded and transcribed. Thematic analysis [41] helped finding main patterns in patient experiences with family involvement. We read and re-read the data and identified potential themes. To promote rigour and credibility, we reviewed and confirmed themes by re-evaluating the dataset. All authors participated in the analysis: (deleted) with (deleted) for the Turkish data; (deleted) with (deleted) for the English data. All authors contributed to writing this paper.

**Family role in two different settings**

This section introduces the hospital settings, focusing on family involvement. Factors include interior architectural design, assumptions inherent in the health-care system, regulation of family involvement, the tasks families undertake, and the ways through which family integration transforms space and rehabilitation practices.

***The Turkish hospital***

This single-storey hospital consisted of a building complex with a parking lot and a garden. A tunnel connected two buildings; the remaining ones dotted the garden. Most fieldwork took place in one of the two connected buildings with about 20 patient rooms, 10 offices and staff rooms, and 2 larger physiotherapy rooms. Patient rooms opened onto a square inner courtyard, which together with the garden served as main area for exercising and socialising. Rooms held either 3 or 6 patients, but housed up to 12 persons, since most patients stayed with an assisting person (spending nights on a recliner). Assisting persons usually were female family members, mostly spouses (TP1, TP3, TP4, TP5, TP6, TP7), but also siblings (TP8, TP9, TP10, TP11), mothers (TP2, TP12, TP13, TP14), children (TP15, TP16), nephews (TP18), or a combination of these (TP19). It was exceptional not to have any family accompanying patients and assisting them with rehabilitation. Where this was the case, other patients’ families willingly provided help. Most considered other patients their “own brothers” (TP11’s sister), loving and taking care of them if necessary (TP2). Space, resources, and labour were all shared. The Turkish health-care system assumes the continuous presence of patients’ families and organises rehabilitation accordingly. Families are expected to undertake various tasks and provide most daily necessities: they support physiotherapy; supply the correct medication at the right time; and help patients with body hygiene. Often they clean bedrooms and bathrooms, and bring, cook and share food.

This collective organisation of space and tasks encourages social interaction, among patients and families and transforms the hospital into a home-like environment. Patient rooms are extensively personalised, with colourful linens, teapots, cups, and snacks for sharing. Researchers entering the room for an interview were welcomed as if they had entered the patient’s home—it is the patient’s space, even if collectively shared. This spatial organisation recreates the “outside” world. Not only the space, but also experiences are shared. Except for rehabilitation routines—physicians’ visits, exercises—daily life is organised like any ordinary day: Patients and family members come together, sit in the garden during good weather, have coffee, gossip, get angry, play music, and fall in love. Even stray cats running through corridors are part of life.

In Turkey, no formal rules delineate family presence within the hospital, nor are the families’ tasks structured. Families do not receive support, and so they feel free to transform life inside the hospital in various ways. As long as they find appropriate ways to accommodate themselves within the hospital, they are left alone.

***The English hospital***

This hospital included several single-storey buildings within a larger garden and parking area. Fieldwork was conducted in two buildings, the amputee and neurological services. The buildings’ interior design resembled any other hospital ward, with long corridors featuring doors to patient rooms. Both wards contained a common room where two corridors intersected. Unlike in Turkey, patients and families needed to go to that room for social interaction. Families did not stay with patients, but visited at scheduled hours (2-8pm). Most family members came every evening, after work, for several hours (F2, F3, F11). On the neurological ward, patients often stayed in single rooms (P1, P2, P8), although sometimes two patients shared a room. The resulting social environment resembled regular hospital wards and reduced opportunities for socialising.

Patients and families summarised family’s tasks as simply “being there”. Yet, they also engaged in other supporting activities—many took out laundry (P1, P2) and brought food (P2, P3, P6). In contrast to Turkey, the NHS system is not based on family presence. Family involvement is welcomed inasmuch it reduces staff responsibilities and supports rehabilitation, but the basic assumption is that NHS staff attends to patients’ needs (focus-group discussions with nurses). Therefore, hospital space is not transformed into a home-like environment. Families did attempt to personalise patients’ rooms with family pictures and postcards (P1, P2, P8), but the space still reflected that it was “owned” by the NHS and its staff. Similarly, daily life was aligned with rehabilitation routines, rather than ordinary life. The singing, chatting, and gatherings in the garden—highlights of Turkish patients’ daily routine—were largely absent. Beeping staff call buttons dominated the hospital’s soundscape.

Involved families’ presence was regulated through signing in and out visiting times, filling in necessary paperwork, and interacting with patients in line with staff’s risk assessments (F2, focus-group discussions with doctors). Thus, the English example differed from the Turkish case: not only in depth and degree of family involvement, but also the extent to which this involvement was formalised within rehabilitation practice. The following analyses these two settings’ impacts on the experiences of people with disabilities.

**Results: first-person perspectives on family involvement in rehabilitation**

***Family involvement as form of dependency***

The continuous family presence during hospital rehabilitation in Turkey continues during post-rehabilitation, with most people with disabilities living with their families, who support them economically and otherwise. Family is hence “an incredible support. Its love, respect and support mean everything to you. You live through and get over this tragedy with them” (TP2, male, 30s, SCI, former patient). TP6 (male, 30s, SCI, former patient) confirmed that his spouse accompanied him through everything. TP3 (male, 40s, SCI) stated that his wife was “his biggest chance”. As TP19 (male, 20s, SCI) attests, any improvement was “due to [his] spouse’s help”.

However, this is very much part of the infantilising and disabling ideologies marking Turkish society’s attitude to people with disabilities, and rehabilitation itself. A doctor confirms:

[The family] is the key [to rehabilitation], because the patient is psychologically feeble. People close to her/him know the patient much better than we do, understand her/his reactions, and should therefore cooperate with us (TD2).

This infantilising attitude is directly reproduced within the family. Another doctor attests: “[Spouses] behave as if they were their [people with disabilities] mothers, and this pleases them. Families treat them like children, as if they had a mental problem” (TD4). A long-time patient (TP25, female, 40s, SCI) remembers how her family would not let her do anything, “even if I actually could do it”. “When I first wanted to help them in the kitchen, they used to tell me ‘you rest, what you can do in two hours, we do in five minutes’”. TP25 describes her family as “very emotional, [and] too protective”.

This approach triggers a paradoxical (mutual) dependency: Although rehabilitation primarily aims to render the disabled person independent (TD5), how it is organised and applied in Turkey keeps the latter dependent on others. Gender also plays a strong role here. It is common in disabled-husband/assisting-wife couples that “no one [be] left in my life except my wife” (TP5, male, 50s, SCI), and wives’ lives become “indexed” to their husbands’ (spouse of TP3, male, 40s, SCI). This dependency also extends to other situations: As TP8 (female, 40s, leg amputation) explains, “[when her sister was leaving], I immediately started to wait for her to return, as I was incapable of doing anything myself. I felt abandoned”.

Oftentimes, this dependency results in the disabled person’s loss of a separate individuality. The rehabilitation narratives of many attendants (spouse of TP3, male, 40s, SCI; mother of TP13, male, 20s, SCI) point not only to sharing space and experience, but also blurred lines between patient and family: “Two months have passed since the operation, we are doing our exercises, waiting”, says the spouse of TP3. The non-medical staff member and former patient NMP1 (male, 30s, SCI) asked:

You think that someone who becomes disabled and comes to the hospital may establish a life for herself/himself? It is the family who does this in Turkey […] Our choices are made by our families, who most probably decide where we should live.

This also results in the loss of intimate spaces and moments:

One day I asked myself: Is this disability? Will I not be able to stay alone? I won’t be able to daydream; I won’t ever have a girlfriend? (TP20, male, 40s, SCI)

TP20 escaped this situation by asking his family to retreat. Doctors helped convince them that he should live by himself, as did the psychologist of TP25 (female, 40s, SCI). For both TP20 and TP25 rehabilitation unfolded as process of negotiation with family; they had to persuade them that they could and should live and work alone. Social worker TNMP2 confirmed that she often backs up patients in their negotiations with relatives. In cases where family presence is overwhelming, the disabled person’s independence becomes possible only after the loss of relatives:

‘My son is disabled now; he won’t be able to do anything henceforth’. That’s how my mother thought. She was not very educated. She used to say so when people came around. […]‘My son cannot marry, I cannot have a grandchild’ and alike... Four years I was oppressed by this viewpoint. When the ‘viewpoint’ died, I came into view. I started going out, be more independent, earn money, go out with girls (TNMP1, male, 30s, SCI).

***Family involvement as form of support***

In the English hospital, visiting family members do not have a formal role. However, they are indispensable for patients, and any absence is noted and resented (P10, male, 70s, neurological service). As one interviewee said: “it means the world to me, the fact that they would go out of their way to come here” (P6, female, 70s, amputee). Many patients responding to a question about family role expressed this sense of vital support: “just keep morale up” (P1, male, 70s, neurological service), “make me happy” (P2, female, 40s, neurological service), “just being there” (P4, female, 70s, amputee).

Families are an anchor who give feedback and guidance: “You can talk things through with them, as in what’s happened with your rehab and stuff, and they can tell you what they think” (P1, male, 70s, neurological service). They may also act as emotional buttress (participant-observation with P3, female, 70s, amputee; F3), as P3 said of her husband:

If I’m upset he’s always here for me… I feel upset today because I don’t feel right. Now if he were here, I would tell him. I phoned him. I know that sounds silly to some people, but he’s my lifeline (P3).

Newly disabled persons may experience a deep sense of insecurity, feeling worthless or unlovable: Are they the same person? How will they cope in the future? (P3) Usually, families’ reactions were supportive: “My son said, ‘We don’t want your leg. We want you, mum’” (P4, female, 70s, amputee).

In the absence of required tasks, almost all families took care of laundry, although the hospital provided such services. Laundry seemed to symbolise the emotional support people were eager to express. Other tasks included washing the person (F2), cutting fingernails (F1), and shaving, cutting hair, or putting on make-up (F8a, F8b). Closest relatives did these tasks so that their family member could maintain her/his sense of self before other visitors outside that intimate inner circle. It was as common for men to support their wives in this way, and vice versa:

[…] we’ve been married 52 years […] we do everything together, so, yes, I think I should be at a bit of a loss if I didn’t come every day. We also phone each other up. Phone five times a day as well (F3).

Being there daily became a symbol of enduring bonds, as one husband said: “I come every day… I didn’t go one day, and I found it more difficult sitting at home not seeing her than what I did seeing her” (F11).

Some patients were without family. Others had complicated relationships: “If I ask her to pop to the shop for me, she doesn’t do it, or if she does, she complains” (P10, male, 70s, neurological service). One relative reported worries about her sister’s husband: “I think he blames her, he thinks she should be trying harder…” (F8a). This patient had lost hope and saw no progress; it was difficult for staff or family to motivate her.

However, most patients are keen to regain their independence. Many are uncomfortably aware of family’s financial and time commitments: “[…] they’ve all got their own commitments, so I don’t want them to go out of their way every single day, to make sure I’ve got company” (P6, female, 70s, amputee). P6 was planning her return to the community with a prosthetic. “I’ve got to learn and do everything for myself. Not to have to rely on somebody doing it for me”.

Many expressed anxieties about being alone or unwanted: “Lying here you think all sorts of things [starts crying] … Like they’re never going to come” (P1, male, 70s, neurological service). Another respondent expressed common feelings of desperation:

I don’t know if things are going to get any worse. My eyesight has diminished ever so much since the stroke. I get very despondent. Loneliness I’ve never felt, I’ve been lonely before many times in my life, but I’ve never felt lonely […] Now I feel it as loneliness, it’s despair sometimes. […] Nobody told me what a stroke entails when I had it (P10, male, 70s, neurological service).

As result of the brain injury, and perhaps also the dependency which long-term hospitalization induces, he feared he could no longer survive in the community: “I’ve no confidence now, whereas before I was self-confident in everything I did. That’s what worries me about getting discharged and going back to the flat. How will I cope?”

Some fears concerned significant others’ reactions to their changed situation. P3 (female, 70s, amputee) worried about her husband’s reaction to her leg amputation:

I did say to him one day, “Oh, I’m so sorry about this” … I said: “You’ve only got half […] a woman, if you call it”. He said: “You’ve only had your leg off, don’t worry about that, you’re still the same person”.

She worried particularly about life after discharge, and her husband having to take on a care-giving role: “The only thing that bothers me a bit, is if it’s going to be too much for him”. Fear of being a burden was common (see also P4, female, 70s, amputee).

Being hospitalised for weeks or months meant that normal life was disrupted, and female patients were unable to fulfill their care-giving and relational roles: “I’ve cried ever since I’ve been here… I’ve done nothing, no Christmas shopping, no cards, nothing” (P8, female, 50s, neurological service). She worried because she had been supporting her daughter, who was separated from an abusive partner. She also felt responsible, because “[m]y son cancelled his wedding next year cause of me. I didn’t want him to do that…” Family worries and fear of being a burden in the future emerged frequently: “I wouldn’t want to put that [care-giving burden] on my children” (P8). She deliberately kept strong when with her children, refusing to share her real feelings: “If I feel they need to know, I’ll let them know, but don’t tell them things that will upset them. They don’t need to be upset. If they saw me like this, they wouldn’t leave me”. However, her sisters noticed her real feelings; one said: “I know she gets very lonely and very depressed, if she doesn’t see people” (F8b).

These first-person accounts illustrate that family presence in physical rehabilitation in England is experienced as major form of support, accompanied by fear of losing that support. Families are a significant form of support in Turkey, too, particularly since the health-care system relies on their presence. This form of support emerges as defining feature of family presence in in-patient rehabilitation in England, whereas in Turkey family presence, by creating an environment where disability is associated with loss of individuality and privacy, can be overwhelming.

***Family involvement as enriching the social environment***

Intense family presence in the hospital and post-rehabilitation in Turkey also serves as *the* factor to trigger the intra-hospital socialising and transforms the hospital into a home-like setting. Firstly, family initiates first-time patients’ socialising in the hospital by talking to doctors, nurses, physiotherapists, other patients, and other attendants. Intra-hospital networks of acquaintances empower both patients and families. Networks affect how hospital space is organised and used: food is brought from home or cooked, and shared, tea and coffee prepared and offered. Patients and families come together in the inner courtyard or garden. Especially in the evenings, after the staff leaves, everyone relaxes. Patients chat, joke around, sing, and play musical instruments:

I really liked how we got together in the evenings… we would joke around. People would sing, we would listen. We would chat […] from 8pm to midnight… People with pressure sores came to the hospital for treatment. They would lie face down in their beds. They would be taken to our meeting spot in their beds… Their families would do that (TP3, male, 40s, SCI).

There are good reasons why most patients refer to these moments of socialising and the garden, when asked what they like most about the rehabilitation hospital. In a city as inaccessible as Istanbul, with limited green areas, the garden provides moments of tranquillity and calm. Encounters with other people with disabilities and families help patients feel less lonely. Information is shared through informal chats about the hospital, doctors, proper medication, and physiotherapy. Advice, troubles, and experiences are shared (almost all interviewees). Through these moments most patients come to terms with their impairments, develop humour around the issue, and form intimate relationships:

You look around to see whether among those who care for patients, there is anyone you might be interested in … There were some [patients] who had these experiences. For instance, the friend in the next bed would come around 11pm or midnight… we do not know in which corner he was chatting with his girlfriend (TP4, male, 60s, stroke-related mobility impairment).

TP20 (male, 40s, SCI), being in a romantic relationship with a nurse; TP23 (male, 30s, SCI), being attracted to a woman; TP2 (male, 30s, SCI); and TP12 (male, 40s, SCI) also mentioned this point. Patients without families become part of this network, too, as other patients’ families help and support them (TP11, female, 50s, mobility-impaired).

This setting appears to be of major advantage in a hospital where rehabilitation consists largely of physiotherapy and medical treatment. Many want to stay longer and refuse weekend leave: “The hospital becomes henceforth your home” (TP20, male, 40s, SCI). However, this has two major drawbacks: Firstly, patients are not prepared for an independent future and hold on to the false belief in a complete cure (TP2, male, 30s, SCI). Secondly, if patients do not want to socialise as much, there is no escape. Some patients do not want to stay up late, because they fear they cannot wake up early for physiotherapy: “I came here to recover, not to chat” (TP25, female, 40s, SCI). As explained above, loss of intimacy is a major problem (TP20, male, 40s, SCI) and translates into a range of complaints about others/otherness. Some find “Easterners”—i.e., Kurds—too noisy (TP7, male, 40s, mobility-impaired; TP9, male, 30s, SCI; TP10, male, 20s, SCI; TP14, male, 20s, recovered from SCI), or think that many patients are “not informed enough”, hinting at differences in class and/or cultural capital. TP17 (male, 50s, mobility-impaired) said that in the hospital he liked least “those who come and mouth off”. The table below summarises the two patterns of family involvement and the respective experience of people with disabilities.

INSERT TABLE (below)

**Discussion and conclusion**

This paper aims to introduce a critical approach to family involvement in in-patient rehabilitation. Current literature often focuses on Western settings where such family involvement is relatively limited, despite recent emphasis on family-centred care. It often exalts increased family involvement and highlights appropriate ways of integrating families more. Here, we refrain from seeing family participation as purely “good” or “bad” [23], but intend to show that the nature of participation determines whether persons with disabilities experience families as enabling or disabling.

As the literature suggests, family involvement can facilitate easier transition to home [12], but our interviews demonstrate that persons with disabilities can perceive family as overwhelming and producing dependency even after discharge. Both families and patients appreciate family participation 13.]; yet, from the perspective of the person with disabilities, convincing family to step back may also feel like *the* key aspect of rehabilitation, bringing life one step closer to “normality”. These findings help develop a critical approach to existing practices in Turkey—rendering family participation so central that it leads to loss of independence and individuality—and England—assuming that increased family participation is beneficial for almost all parties involved. The existing literature criticises the increased family role due to neo-liberal, structural changes in health-care contexts, which increase family responsibilities, but do not necessarily empower families [18]. This is a significant point. We argue that there is value in developing a disability-rights-informed critical perspective about family involvement from the standpoint of the experience of the person with disabilities [23].

Furthermore, our research shows that family presence in the hospital throughout rehabilitation produces an environment where hospital wards start resembling spaces of everyday life, where hospital rooms feel like spaces owned by patients and families, and where social interactions resemble the unregulated, spontaneous everyday encounters beyond hospital walls. Our interviews in the Turkish hospital demonstrated that most patients liked this aspect of rehabilitation best: the families’ role in creating intra-hospital socialising, shaped by gatherings, chatting in the garden, evening meetings, dating, flirting, and the like. This family role seems to accomplish the opposite of the dependency-producing, suffocating impact described above. Interviews in both settings reveal the significance of such unregulated encounters. This alerts us to the difference of rehabilitation from any other, regular treatment process: it takes longer and aims at facilitating transition to life with a new bodily status. Thus, rehabilitation hospitals need to look different from other hospitals. Existing studies on rehabilitation and family overlook this point. Hence, scholarly work on family role in rehabilitation can benefit from research on diverse health-care arrangements and cultures, with greater emphasis on the experiences of people with disabilities. Furthermore, focus on the particularities of in-patient rehabilitation as process contributes to rehabilitation theory, not only enriching discussions on family role, but also understanding rehabilitation practices more broadly.

This research has several limitations: First, fieldwork in Turkey originally did not concern family role. Only after completion and initial data analysis did family role emerge as important axis of discussion. In contrast, fieldwork in England centred around family role in rehabilitation from the very beginning. This made comparing the two case-studies difficult; the Turkish data’s analysis required particular effort to retrieve relevant information. Second, populations were not identical: SCI patients in Turkey versus (generally older) amputation and neurological rehabilitation patients in England. Third, methodologically fieldwork in Turkey comprised ethnography—casual conversations, participation in everyday life, informal socialising, and in-depth interviews. In England, we conducted interviews and focus-group discussions and observed five families during their visits. The divergent data collection strategies had practical reasons. A Turkish researcher, restricted by time and funding limits, conducted fieldwork in England. Presumably, a synchronized methodological approach would have generated more fruitful comparative results.

Regardless, useful conclusions can be drawn for clinical practice: First, family participation in in-patient rehabilitation is important. Yet, clinical practice needs to ensure that families are involved in ways that facilitate the transition of people with disabilities to a new life, rather than producing dependency, which the disability movement and scholars have combatted for decades [42]. Second, the experiences of people with disabilities reveal that less regulated environments—i.e., settings that resemble life outside the hospital—can support successful transition. This relates to in-hospital relationships and socialising which disabled patients find emotionally nourishing and which certain forms of family presence can help generate. Finally, whenever ways to increase family participation are discussed, the standpoint of people with disabilities and their experiences with family presence should not be neglected.

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The authors report no declarations of interest.

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**Table: Family Role in In-Patient Rehabilitation in Turkey and England**

|  |  |  |
| --- | --- | --- |
| **Country** | **Family Role** | **Disabled People’s Experiences** |
| Turkey | * Health-care based on family presence
* Family role intense, with multiple tasks
* Families stay with patients
* Collective (shared space, resources, labour)
* Unregulated family presence
 | * Loss of privacy and individuality
* Overwhelming family presence
* Reproducing dependency
* Socially enriching
* Rehabilitation similar to life outside hospital
 |
| England | * NHS system not based on family presence
* Family role less intense, with fewer tasks
* Families visiting patients
* Limited socialising
* Regulated family presence
 | * Emphasis on independent living
* Supportive family presence
* Fear of losing family support
* Relative social isolation
* Rehabilitation similar to any other hospital ward
 |