



# Disabled Women's Care Experiences in Turkey: Intimacy, Dependency, Independent Living

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**RESEARCH**



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## ABSTRACT

The literature on care relationships and independent living is extensive, although geographically limited, and focuses predominantly on the UK, Scandinavia and the US. This paper explores these themes in the context of Turkey. Through a case study approach, it analyses the experiences of three disabled women with distinctive care arrangements (paid professional, familial informal and an eclectic mix). Cases are discussed in relation to the Turkish context and the existing literature. The paper argues that the experiences of disabled Turkish women need to be understood in relation to the Turkish political economy of care (dependent on family support and undocumented migration), cultural aspects of care (shaped by gendered imagery) and the development of disability rights (characterised by limited independent living). Recognising such universal and locally specific aspects of care and independent living across geographies will contribute to a fuller understanding of disabled people's experiences and enhance theories of care.

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Social care policy, care relationships and independent living (IL) have received extensive scholarly attention in recent decades, showing that the way support is conceived, funded and administered will determine whether the rights of disabled people are realised or denied. Disability studies scholars, and those directly associated with the disabled people's movement, have drawn attention to many problematic assumptions underlying the concept of care, arguing that it is a 'form of oppression and act of prejudice' that obstructs and hinders independent lives (Morris 1997). In more recent decades, personal assistance (PA) through direct payments has emerged as the principal policy means of ensuring the rights of disabled people by alleviating the negative imagery surrounding dependence and by providing disabled people with choice and control in all aspects of their support arrangements (Ratzka 1996).

PA differs from country to country. This variation includes the extent to which PA is enshrined in legislation, how it is funded, the style of service models and eligibility criteria (Nally, Moore & Gowran 2021). A full review of this international variation is beyond the scope of current discussion (see Askheim (2005) for a comparison of PA schemes in the US, the UK, Sweden and Norway; Christensen (2012) comparing the UK and Norway; Tschanz (2018) comparing Switzerland, Germany, the UK and Sweden). An important point, however, is that not only do countries vary in the way PA is legislated, funded and administered, but also these factors shape the PA relationships that ensue. For example, Christensen's (2012) study of Norwegian and UK cash-for-care relationships reveals that the individualised employer role prominent in the UK encourages extremes of either master/servant or solidarity/emotional-based relationships. The Norwegian funding and administrative model, by contrast, supports more sustainable hybrid relationship combining friendship and paid care work. Context matters, but so too does an appreciation of universal features of support and independence. Despite the national differences indicated above, the international profile of PA generated by Mladenov (2020) shows that the markers of good and bad PA transcend borders and speak to universal concerns faced by all disabled people. PA and independence need to be understood, therefore, as something akin to a universal experience shaped by national contexts.

While existing literature on the experience of care and PA is rich in empirical (Askheim 2005; Christensen 2012; Porter, Shakespeare & Stockl 2020) and theoretical contributions (Bostad & Hanisch 2016; Hughes et al. 2005; Watson et al. 2004), it lacks geographical and cultural diversity, focusing primarily upon the experience of disabled people in North America, the UK and Scandinavia (exceptions include Mladenov (2017) on Bulgaria and Wang (2007) on Taiwan).

This paper addresses this geographical and cultural lacuna through a case-based study of three Turkish disabled women. Each case speaks to a distinctive care arrangement (paid professional care, informal familial care and an eclectic arrangement including PA), and together, they address distinct points of interest. First, this paper explores each arrangement's troubling and positive aspects, as expressed by the disabled person; second, it relates each case within the contextual background of Turkey; finally, it situates this discussion within the scholarly work on care, IL and PA. The paper argues that the Turkish experience of care and PA reveals both universal and locally specific characteristics. Each woman reported complex interpersonal care relationships and the desire for IL, yet these were expressed through, and are shaped by, local political and cultural economies of care and the relative prominence of the disabled people's movement and the philosophy of IL. In what follows, we introduce the Turkish context, present our methods, explore the cases and conclude with our final discussion.

### **TURKEY'S POLITICAL ECONOMY OF SOCIAL CARE**

Within the welfare regimes literature, Turkey, along with Greece, Portugal, Italy and Spain, represents the Southern European Model (Buğra & Keyder 2006; Gough 1996), where the welfare is reliant upon family support (Martin 1997). Social care is not seen to be a duty of the state, unless family are unable to provide support (Akkan & Serim 2019).

The social care services that do exist comprise three key elements: first, since the 1990s, the state provides limited institutional care (Atasü-Topçuoğlu 2021: 17, 18). Second, since 2006, the state has begun outsourcing care services to private firms, which establish rehabilitation and care centres, the funding for which is equivalent to double the minimum wage per disabled

resident per month (Akkan & Serim 2019: 10). Third, in 2007, the state introduced a cash-for-care scheme with three eligibility criteria: (1) the care provider must be a family member; (2) the disabled person must have minimum 50% impairment, as certified by a public health institution; (3) the total household income must be lower than two thirds of the minimum wage (Akkan & Serim 2019). Thus, cash benefits are accessible only to those with severe impairment and who face extreme poverty (Atasü-Topçuoğlu 2021: 19).<sup>1</sup>

This structure indicates a care deficit in Turkey, as the choice and control of disabled people who wish to live independently from family or institutions is denied, unless they meet these severe qualifying conditions. Two phenomena fill in this lacuna: undocumented migrant workers and unpaid family care.

Since the 1990s, Turkey has become a destination for migrants arriving from the post-socialist countries of Eastern Europe, the Caucasus and Central Asia to be employed in care work for older people, disabled people and children (Akkan & Serim 2019). Two aspects of this are significant for care relationships. First, migrant domestic workers often have an undocumented status (Akalin 2015). They arrive with 90-day tourist visas, stay until these visas expire and then become undocumented workers without any contract or a formal employee status (Akkan & Serim 2019).<sup>2</sup> Second, the migrant domestic worker is typically a ‘floating body’ (Akalin 2015: 66)—in continuous movement between Turkey and her own country<sup>3</sup> or on route to Europe through Turkey.

These two aspects—the non-contractual/undocumented and the floating/transitory status of the migrant worker—have significant impact on care relationships at the micro-level. First, they create an unpredictable (and potentially unsafe) basis for care relationships, with implications for the stability, reliability and duration of the relationship. Second, the non-contractual status of the migrant worker contributes to the boundaries between employee and family member becoming blurred (Akalin 2015: 68). Akkan and Serim (2019: 4) explain that, in Turkey, commodified care relationships frequently display familial characteristics:

[T]he care worker calls the care receiver ‘mom’ and the care receiver refers to the care worker as my daughter, my lifetime friend etc... Sharing the home space on equal terms, eating meals together and sitting at the same table is seen as an illustration of a good commodified care relationship.

As our data will demonstrate, these features of care—feeling unsafe and the familial analogues—are interrelated. Conceiving of the worker as a family member helps reduce the anxiety of feeling unsafe.

## GENDERED DYNAMICS OF SOCIAL CARE

In her eminent 1988 article, Kandiyoti classified Turkey as a system of classical patriarchy (278). This system is characterized by dominant male values and the patriarchal extended family, where relationships of domination define not only exchanges between men and women but also intergenerational relationships among women in the same family (278, 279), where younger women are expected to show care and respect to the older generation (Can 2019: 88). As such, understanding structures of familial care requires a gendered as well as a gerontological lens.

Parallel to developments elsewhere, in Turkey major transformations such as ‘the impact of new market forces, capital penetration in rural areas’ (Kandiyoti 1988: 281) and women’s

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1 The 2021 statistical bulletin published by the Directorate of Disability and Elderly Services indicates that as of August 2021, 535,805 disabled people benefited from this scheme. In Turkey, reliable statistics on disability is an ongoing problem. For instance, the same bulletin suggests that disabled people comprise 6.9% of the total population in Turkey (4,876,000 people as of 2011). Simultaneously, a 2002 study conducted by the Prime Minister’s Office’s Administration for Disabled People (Özürlüler İdaresi Başkanlığı (ÖZİDA)) determined the same percentage rate as 12.29. Both figures indicate that a majority of disabled people in Turkey remain excluded from social care services.

2 Since 2011, the state attempted to include undocumented migrants in the formal labour market. Still, many migrants continue to work without contract (Akkan & Serim 2019: 13, 14).

3 This movement is necessitated by two circumstances: first, as part of the global care chain (Hochschild 2000), the migrant care worker visits the family she left behind. Second, the monetary fine paid at the border renews the migrant worker’s tourist visa and legitimates another 90-day stay in the country.

increased participation in the labour force (Can 2019: 88) have instigated a 'break from the extended family pattern' (Kandiyoti 1987: 332), contributing to a gradual breakdown of the classical patriarchal system (Can 2019; Kandiyoti 1988).<sup>4</sup> Nevertheless, the 'patriarchal division of labour at home remained intact' (Can 2019: 90) and the association of women with nurturing roles persisted. Atasü-Topçuoğlu (2021) refers to a gendered imagery of care in Turkey (13) and argues that this imagery is reinforced by an Islamic discourse that 'brings about norms and institutions that continuously organize one's private sphere in terms of spatial gender division and gendered roles...' (Tuksal 2018 in Atasü-Topçuoğlu 2021: 16). As such, care is closely associated with intimacy, family and, particularly, the women in the family. Among these women, mothers, as the archetypal nurturing figure, hold a special cultural status, which is reinforced by both the political discourse in Turkey and the gendered imagery of care more broadly (Atasü-Topçuoğlu 2021: 15–16).

At the political level, women's role as mother is emphasised by the governing Justice and Development Party, with encouragement for couples to have 'at least 3 children',<sup>5</sup> designating 'good Muslim women as altruistic mothers responsible for the family' (Atasü-Topçuoğlu 2021: 16). Culturally, the mother-child relation symbolises the 'ideal care' relationship (Atasü-Topçuoğlu 2021: 15) to the extent that characteristics typically associated with a 'caring mother' inform other kinds of care relationships. For instance, during her fieldwork with migrant domestic workers, Akalin (2015) observed that many employers identified motherhood 'as the ultimate skill in care work' (74) and consequently sought workers who were themselves mothers.

Motherhood also takes on a distinctive meaning and practical form in the context of disability. In practical terms, when compared to older people, it is more likely that the mother of a disabled person will be alive and capable of an active caring role. There is an expectation, therefore, that mothers will play an active role in supporting their adult disabled children. Second, in Turkey, where there is not a strong disability movement to question the infantilising aspects of care, the image of the mother as the carer of her impaired adult 'child' is almost a cultural norm (Atasü-Topçuoğlu 2021: 15). This also implies that male involvement in care is rather uncommon. Bolak (1997) asserts that 'it is only when a female support system is not available or when it becomes a mixed blessing...that the potential for involving men in family work emerges' (429).

Still, caution and sensitivity to variation is warranted. The aforementioned transformation of Turkey's economy and society has facilitated the outsourcing of traditional caring and domestic work among upper-middle class women to others (Atasü-Topçuoğlu 2021: 14), either to the migrant domestic workers (live-in care) or to lower-middle class Turkish women for daily live-out services (Akalin 2015: 68). Thus the lines between intimacy, family and care may be transgressed when needed, or when social position affords.

## DISABILITY RIGHTS AND IL

Broadly speaking, Turkey is characterised by a limited conception of IL (Ünal 2019) and the profound exclusion of disabled people from education, the labour market (Yılmaz 2020) and urban spaces (Yardımcı & Bezmez 2018).

Despite this, there is a dynamic and complex picture of disability rights in Turkey. In the 1990s, new debates on citizenship allowed room for the development of a new language of rights (Kadioğlu 2007), and at the turn of the millennium, disability emerged as a field of interest at both local (Bezmez & Yardımcı 2010) and national levels. Thus, the early 2000s witnessed a shift to a rights-based disability discourse (deleted) and policy: particularly Turkey's 2009 ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) and the introduction of legislation in 2005 requiring all public spaces to become accessible within seven years (Yılmaz 2020). Furthermore, increased use of the Internet stimulated online disability activism (Bezmez & Yardımcı 2010), all of which created an optimistic environment for a more democratic and inclusive understanding of citizenship.

This optimism could not be sustained. In the context of a broader erosion of democratic rights, especially since the second decade of the new millennium, rights-based approaches to disability slipped into the background. Significant problems remained at the enforcement

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<sup>4</sup> In this light, Can (2019) draws attention to the increasing role of grandmothers in caring for their grandchildren as the younger generation of women assume full-time employment.

<sup>5</sup> <https://www.cumhuriyet.com.tr/haber/her-ailede-3-cocuk-olmali-91590> (accessed May 10).

and implementation levels of the CRPD: the deadline for the 2005 legislation was postponed innumerable times, the excitement surrounding disability online activism remained relatively ineffective in substantive terms and disabled people continued to face widespread discrimination (Yılmaz 2020).

Several reports prepared by the Disabled Women's Association (*Engelli Kadınlar Derneği* (ENG-KAD)) indicate that hardships endured by disabled women deserve special attention (Şenyurt et al. 2016; Engelli Kadın Derneği. 2014). Disabled women remain on the fringes of both disability NGOs and women's groups: the former are dominated by disabled men, and the latter's familiarity with disability is limited. Disabled women, therefore, lack role models upon which to model equal lives, and with disabling barriers being so widespread and entrenched, the prospects of IL is minimal.

## METHODS

This paper presents three cases, which each illustrate distinctive care arrangements (professional care, familial care and an eclectic combination including PA). The three cases were selected from an initial round of in-depth interviews with five disabled women. These interviews were conducted during pilot fieldwork, which aimed to identify specific research questions and areas warranting further exploration in future studies. This current (pilot) study received ethical approval from Koç University's Ethics Committee.

## PARTICIPANTS AND DATA COLLECTION

All women were wheelchair users between the ages of 32 and 50. One participant relied on professional assistance solely, two lived with family carers and two had eclectic arrangements comprising both family and professionals. Four women were single; one was married. Four participants were graduates of higher education. Three were employed full-time, one had a part-time job and one did not work.

Participants were accessed through the researchers' existing disability networks. Interviews were conducted in July 2019 in two cities in Turkey and lasted between 25 and 100 minutes in duration. Informed consent was taken, and questions surrounding two key themes were asked: (1) participants' experiences of their daily care arrangements and (2) these experiences' relation to the wider Turkish context. All interviews were audio recorded and transcribed verbatim. Each participant was given a pseudonym.

## DATA ANALYSIS

The three cases were selected on the basis of practical and conceptual considerations. A first round of data analysis revealed that one of the interviews did not substantially contribute to existing knowledge. This was so because during the course of the interview, the participant became fatigued and the interview was cut short, meaning the data generated was very limited. A second interviewee's data overlapped with significant portions of the three remaining interviews. This interview did discuss professional and informal care, but these themes were discussed at greater length, and in more detail, in the three remaining interviews. Thus, three interviews were selected for further analysis according to a case study approach.

In this approach, in addition to concentrating 'on experiential knowledge of the case', we paid 'close attention to the influence of its social, political and other contexts' (Stake 2005: 444). We acknowledge the limitations of a case study approach providing data that is not generalisable. Yet we do not intend our analysis to represent definitive, general accounts of care and independent living. In line with Stake's (2005) emphasis on the use of qualitative case studies 'to optimise understanding of the case rather than to generalise beyond it' (443), we present each case as an illustration of distinctive forms of care in Turkey. We suggest that our findings have value in their own right and can support and inform further relevant research in this area.

## FINDINGS

In the following section we present the cases of Defne, Melis and Leyla. In each case we discuss the relational dynamics of care and consider their implications for IL in the Turkish context.

Defne is a 49-year-old woman with a spinal cord injury resulting from an accident at the age 16. Defne's mother died two years before her injury, and her father abandoned the family soon after her death. Defne has two married siblings who live nearby but rarely provide hands-on support. For the past couple of years, Defne has lived with a professional carer—an immigrant from Georgia. Despite being employed (and funded) by Defne, this professional care relationship does not resemble PA: the philosophy of IL is almost entirely absent, and the relationship is marked by a complex interplay between intimacy and dependency.

### Professional carer as source of intimacy

When asked about her experience of her professional care relationship, Defne's initial response was very positive. Theirs was an intimate relationship, marked by mutual affection, and their time together was often spent enjoying social activities. Defne explained that she valued the youth, energy and companionship that her carer brought to her home:

It is so nice to have someone in the house...In the past [when Defne lived alone] ...I used to have the TV on, so that there would be a sound... Loneliness is not nice.

This conviviality and intimacy extended to Defne's close family: her sister, brother-in-law and their children all experienced a sociable relationship with the carer. These dynamics meant Defne likened this caring milieu to a family: 'My brother-in-law perceives (the carer) as "his own daughter"', and she also described her own communication with the carer as a 'sister-sibling' relationship.

The administrative aspects of their relationship were similarly informal. Defne detailed with an appreciative tone how she had never formally discussed her carer's holiday allowance, rather she could take days off 'as she wished'. This flexibility was mirrored in the actions and expectations of the carer, who Defne said would provide support within Defne's wider social network: 'We are so close...For instance, my sister's balcony was untidy, dirty. (The carer) comfortably said: "Sister, one day I should come and tidy the balcony up"'.

For Defne, these acts of giving and receiving support and affection mean that, to a large extent, the administrative and emotional boundaries that one might expect within a professional care relationship melt away.

### Professional carer as source of distrust

As Defne's interview progressed, she began detailing this relationship in more complicated and troubling ways. There were minor complaints, such as her carer's appearance and the standard of her work, but also more fundamental concerns.

Most significantly was Defne's feelings of distrust, which stemmed initially from her sense that the carer was 'secretive': she did not share details about her personal life; whereas, Defne disclosed highly intimate information. This asymmetry of personal disclosure (Porter, Shakespeare & Stockl 2020) was exacerbated by the language barrier between both women, and Defne reported feeling suspicious of her carer when she answered her phone in Georgian rather than Turkish.

Defne's feelings of distrust were also rooted in her concerns over her carer's financial circumstances and the creeping costs Defne feared being exposed to:

I started paying her 400 US Dollars, but it's not enough. Her debts are endless... She has a lot of responsibilities (family in Georgia) ... but if that is not the case, then I leave her to God...

She continued:

I am not printing money; I give two third of my salary to her... and I have to pay the rent, for everything we eat and drink, heating, water, internet, phone (a big sigh) ... Do you know how long it has been since the last time I bought something special for myself?

These financial concerns further heightened Defne's unease over her carer's undisclosed personal life. Specifically, Defne questioned how her carer could afford expensive jewellery and make-up, which the latter described as being gifts from friends. 'What kinds of friends are

these?’ adding, ‘No, it’s not sitting well’. In perhaps the most striking indicator of her distrust, Defne said, ‘It is like, one day I will come home and won’t be able to find her’.

Defne’s experience of professional care is far from liberating or empowering. Her interview paints a picture of a care relationship that, although intimate, is troubled by practical problems and feelings of distrust. Nonetheless, the complex configuration of practical and emotional co-dependency means that this relationship is also extremely difficult to end, to transform or to replace. In Turkey, a general cultural understanding that care should be provided by family members prevails, and relatively speaking, professional care is still understood to be a least desirable resort. Thus, for the disabled person, professional care relationships often begin and develop under the dual burdens of personal financial costs and the absence of familial support. The intimacy offered by the professional care relationships need to be understood against this backdrop: meeting a practical need left unfulfilled by absent family and as a coping mechanism rendering the ‘last resort’ of professional care somewhat more bearable.

### **MELIS: MOTHER AND DAUGHTER AN ‘ALMOST IDEAL COUPLE’**

Melis is a 49-year-old woman with tetraplegia resulting from a car accident at the age of 18. Melis lives with her parents, whilst her wider family, who provide occasional support, live just one block away. Melis has a two-year college degree and works part-time at a major Turkish newspaper. Although Melis has some previous experiences of professional carers, her long-standing support is provided by her mother, whilst her father has ‘nothing to do’ with her care.

#### **‘Wherever I go... she always follows’**

Melis’s account of her relationship with her mother was largely positive. There is a deeply intimate relationship, which Melis illustrated in saying, ‘My mum understands what I am trying to say from the look in my eye and the tone of my voice’. As Melis described their relationship, it became clear that it was characterised by the fact that Melis’s needs, wishes and preferences are always prioritised by her mother:

For instance, even when she stopped smoking, she helped me smoke... she does not drink alcohol, but she comes with me to the bar... wherever I want, she comes with me even to places, she does not like..., she would be behind me, rushing wherever I go, with no complaint, she always follows.

Melis contrasted this relationship with her impression of professional care relationships. A professional carer, she said, was a ‘stranger’, adding ‘there will be many things, you will not want to share’.

Concerns over safety were also central to Melis, and she recalled one particularly ‘scary’ experience with a professional carer—the ‘sister from Giresun’ (a Turkish city):

The sister from Giresun... I swear I was scared... The woman was talking about something related to organ dealership... She... points at a message she received on Facebook and says ‘this man...how does he know I am a widow?’...I deliberately caused problems, so that she would go.

#### **‘Subtle’ concerns**

When asked whether there are any problematic aspects of this relationship with her mum, Melis replied definitively, ‘None... very clear’. Yet at other times, Melis’s account hinted at a more complex experience. Towards the end of the interview, Melis stated that because she is the ‘dominant character’ of this relationship, she worries that she has ‘blocked’ her mother’s life.

Melis also worries that her care (lifting/transferring) places great physical strain upon her mother and explained that she smokes cigarettes as way of managing her weight: ‘I quit smoking for about 1.5 years...I put on a lot of weight...I started smoking again, because it helps me lose appetite’.

Yet in Melis’s account, these concerns over her mother’s freedom and wellbeing remain marginal due to her belief that their relationship involves a natural (unequal) equilibrium: ‘She is the giving side. I do not believe there could be equality anyway’. Reflecting on these concerns, Melis summarises by saying ‘the rest (putting these concerns aside), my mother and I are the

ideal couple'. Thus for Melis, the maternal care relationship, despite the respective concerns, remains permissible, sustainable and enjoyable.

Melis's experience should be understood within the boundaries of Turkish cultural and political economies of care. Most importantly here is the cultural, institutional and economic nexus surrounding the mother as the ideal caregiver. This near archetypal example illustrates how mothers typically meet the support needs of their adult disabled children and, therefore, fill the care deficit within the Turkish state. This case also demonstrates the positive features of such support relationships: not being exposed to the financial costs of care or the stigmatised status of resorting to professional care, and intimacy and trust common to positive filial relationships. Yet also clear are Melis's (albeit muted) concerns over her mother's health and wellbeing, the strain that care places upon both parties and the unavoidable fact that Melis lacks any choice of alternate support arrangements. This support relationship exhibits positive features, but it is also one that exists through necessity.

## **LEYLA: ECLECTIC CARE RELATIONSHIPS AND THE (IM)POSSIBILITY OF PERSONAL ASSISTANCE**

Leyla is a 32-year-old woman with congenital muscular dystrophy. Leyla lives with her parents, and whilst her mother provides the significant majority of her care, her father is also involved. Leyla has a PhD in Clinical Psychology (combining disability studies), and she is also active in European and North American disability networks. Unlike Defne and Melis, Leyla is familiar with the idea of PA (as conceptualised by disability scholars and activists) and has had direct experience of PA, having received funding to attend the European Network on Independent Living's (ENIL) meetings. Leyla is therefore in a unique position to provide insight into familial care dynamics and the possibilities afforded by PA in a Turkish context.

### **'Mecbur olmak'—A sense of imposed entanglement**

Leyla described the supportive relationship with her mother as being relatively 'strained' due to Leyla's own feeling that she relied too much on her family for support. As she explained these feelings, Leyla used the Turkish expression 'mecbur olmak'—a verb expressing coalescing feelings of dependence, being in need of someone or something, and also a sense of being trapped. *Mecbur olmak* defies direct translation but may be understood as a form of 'imposed entanglement'. This dynamic characterised Leyla's familial care relationships in several ways. First, is Leyla's sentiment that her needs ought to be fulfilled immediately:

There have been times, when I wanted things to get done immediately... I had the impression that everybody else's needs were being satisfied right away, except for me.

This 'someone' was invariably Leyla's mum or dad, and Leyla explained how the sense of imposed entanglement was shared by Leyla's parents, especially her mother, who felt that she should be at Leyla's disposal at all times.

Second, this sense of imposed entanglement made it difficult for Leyla to go against her parents' wishes. In one example, Leyla described her mum as a 'believer' and explained that it took until the age of 25 before Leyla felt she could refuse her mother's expectation that she observe religious practices:

Occasionally, when mum would go like 'C'mon, perform the prayer', it took me 25 years to be able to say 'I will not do it'... or for instance... the first time I did not fast, mum did not talk to me for about a month... but she continued preparing the breakfast (laughing)... It made me think 'she still cares for me, I won't die out of this. I think I can bear with her not talking'.

### **The (im)possibility of personal assistance**

At the age of 29 (three years prior to the interview), Leyla was introduced to the idea of PA when she received funding to attend ENIL training. Leyla described this first encounter with the philosophy of IL and PA:

This (living with a PA) has never been offered to us as an option... because structurally it has not existed. For me to see this as an option, it was really with that first visit to ENIL's thing (meeting).

Reflecting on this experience, Leyla explained the transformative effects of PA by contrasting it with her experience of family support:

Sometimes what I experience with my family is ... 'I wonder if this is not exactly what they would like to do now?' ... Yet when she (the PA) said 'this (meeting Leyla's needs) is what I am here for', (I feel) 'All right, I can also want something...' and... the costs were covered by them (organisers) ... I think personal assistance is a beautiful thing (laughing).

This beauty, however, is tempered for Leyla by the irony that, without state funding, PA remains an unfulfilled possibility. Yet Leyla explained that simply being exposed to the principles of IL and PA transformed her existing support relationships:

Moving out, living with a PA... Once these started feeling as doable, I started seeing the relationship at home differently... I distanced myself from that sense of imposed entanglement ... That has been a considerable sense of relief.

Leyla's experience of care is marked by a remarkable shift in perspective, afforded by her exposure to PA as an emancipatory model of support and funding (direct payments). PA disrupted Leyla's taken-for-granted assumptions about what support ought to look like and rejuvenated her relationship with her family. Despite not leading to immediate practical changes, this exposure to PA produced a sense of relief and offered Leyla hope for a more independent future.

## **GENDER, CARE AND INDEPENDENT LIVES**

Despite their differences, all three cases share two related commonalities that inform the meaning of support relationships and, to a degree, determine the possibility of independence in Turkey: the gendered challenges inherent to supportive romantic relationships and the enduring image of the mother as carer.

Each woman spoke of the difficulties they experienced imagining or realising romantic relationships with male partners. Melis said that she would not attempt to initiate such a partnership, and Defne, who previously had a fiancé of five years, explained that the breakdown of this relationship had left her feeling financially abused and full of resentment. For Leyla, the challenge of romantic partnership was one that shaped the wider meaning of independence and womanhood:

I think, on the topic of full independence or becoming an individual, I can say that I have a bit of more confidence in myself. But regarding being a woman, still... that 'ableist' side of me... I think I experience that conflict there more often.

Referring to the 'traditional attitude in Turkish society', Leyla said that she felt unable to be 'an ideal wife' because she did not feel 'in a position to give care'. Here the gendered divisions of care not only shape the support Leyla receives but also, in Leyla's view, deny her the possibility of romantic partnership, or even 'being a woman'.

Cultural representations of the mother as ideal caregiver clearly informed the practical and symbolic meaning of independence imagined by each participant. For Defne, the trauma of losing her mother at 14 continued to provide a kind of script through which she made sense of care and independence. The absence of her mother serves to intensify her belief in the mother as the ultimate, ideal provider of care. Imagining how different her life would have been had her mother survived, Defne said mournfully, 'We would have had such a different life'.

For Melis, the difference between male partners and mothers as sources of support could not be more stark, and she explained that when women become impaired, '90 % of men sneak off'. On the contrary, and consistent with the aforementioned deficit of care within the Turkish state, Melis said that women felt 'obliged to' provide support in marriage as in the family:

My observation is that they (women) stay, first, because they are embarrassed (to leave) in front of family, second they are financially dependent and have nowhere else to go.

As outlined above, the lack of state support means that Melis relies on her mother—a supportive relationship she described as an ‘almost ideal couple’. Yet the paucity of alternative support arrangements leads to a further enduring anxiety, as Melis explains:

The horror of ‘what am I going to do if something happens to my mum?’ is always inside me...I have been turning cartwheels to dismiss it, because I feel horror. I do not mean fear, it is a blunt feeling of horror.

In contrast, for Leyla, the experience of PA has broken the symbolic coupling between motherhood and care. Taking control of her support arrangements through direct funding has helped her to reconsider her relationship with her mother. Being set free from a sense of imposed entanglement, Leyla can be part of the care relationship without feeling such pernicious feelings of want and guilt.

## **DISCUSSION**

### **RELATIONSHIPS WITH PROFESSIONAL CARERS**

Shaped by conservative and market values (Akkan 2018), the Turkish political economy of care sees direct-employment care relationships operate without the underpinning rights-based discourse common to Scandinavia and the UK. The paid care relationships discussed in this study are not PA, yet they are relationally complex, and in this sense they share similarities with PA relationships. Defne’s account of paid care resembles a ‘hybrid-relationship’ in which the boundaries between ‘care as work’ and ‘care as feeling’ appear porous (Christensen 2012; Ungerson 2005). This is not a singularly instrumental relationship, and in the same way as has been observed with PA, Defne and her family make sense of this relationship using familial metaphors (Shakespeare, Stockl & Porter 2018). But Defne’s situation is far from ideal: she does not trust her carer and is suspicious of her character. Here, again, there are clear parallels with other direct-employment relationships, where admitting a ‘stranger’ into one’s home comes with uncertainty and risk. These risks are well recognised within the PA and care literature, and strategies exist to mitigate them (Ungerson 1999). But strategies such as employing PAs via user-led organisations or hiring workers via one’s network of other disabled employers requires an established care sector underpinned by legislation and principles of IL, which remain as yet underdeveloped in Turkey (Atasü-Topçuoğlu 2021). The Turkish context also poses distinctive challenges, which likely exacerbate the relational troubles experienced by Defne. The fact that Defne’s worker is an undocumented and transient migrant (the employment relationship lacks contractual safeguards for either party) means that Defne lives with the inherent risk that her carer may one day disappear without warning. Finally, unlike in Scandinavia and the UK, this form of privately funded direct-employment relationship is subject to overt stigma and is seen to be indicative of a family unwilling to provide support. In this context, the intimacy and familial analogues Defne expressed should be recognised, in part, as a means of making this form of support somewhat more bearable.

### **GENDERED DYNAMICS OF CARE**

As normative gender roles remain a significant structuring feature of everyday life in Turkey (Can 2019) and any professional assistance has to be paid out-of-pocket, the representation of the mother as the preferred and idealised care provider acted as an interpretive anchor within each case. For Defne, her experience of paid care was defined, in part, by the absence of her mother; Melis’s close reliance on her doting mother was something she regarded as problematic yet ‘natural’; and for Leyla, PA disrupted normative expectations around this same relationship. There are clear parallels here with feminist scholarship, which makes visible the underpaid, undervalued and unrecognised care work undertaken by women (Finch 1983), and, comparatively, in terms of the function this work plays in sustaining economies and societies across the globe (Orloff 2009). Whilst important, this lens is also problematic, as it risks valorising and reproducing the ‘ideology of care’ and negative imagery of disabled people as dependent. Based upon this small case-based study, which illustrates the gendered nature of giving and receiving support in Turkey, we see value in the assertion of Hughes et al. (2004) that the feminization of care in phallogocentric cultures subordinates participants on both sides of the caring relationship (260). Similar intergenerational gender dynamics shape support relationships in many European countries (Pfau-Effinger 2005) but are, relatively

speaking, more firmly engrained in the Turkish context. Therefore, the twin veils of naturalness surrounding ‘women’s work’ and the dependency of disabled people hides both the need and the means of change, making the oppression of disabled people and female carers potentially more resistant to change.

The gendered dynamics of disability, support and independence appear also to make the prospect of independent romantic lives less likely, as each woman in this study reported diminished intimate citizenship (Plummer 2005). Melis could not envisage romantic partnerships and expressed internalised ableist beliefs when she imagined feeling ‘sad’ for any potential partner; the breakdown of Defne’s relationship with her fiancé left her feeling betrayed and vulnerable; Leyla spoke critically about ableist constructs of womanhood and intimate partner roles in ‘traditional Turkish culture’. The barriers to womanhood expressed or implied within these accounts mirror those of disabled women internationally (e.g., Barron 1997 on Sweden) but demonstrate comparatively modest transgression or rejection of their ableist ideals. In this sense, the experiences of disabled women in this study resemble psycho-emotional disablism, understood as the psychological and emotional dimensions of oppression that operate alongside material barriers (Thomas 2006). Importantly, the oppression the women experience in terms of their gender identity and intimate citizenship concerns not what they can do, but what they can be: full women and active intimate partners. Again, while the complexity and diversity of disabled women’s intimate lives have been recognised in other contexts (e.g., Liddiard 2014 in the UK), the strength of gender expectations expressed by each participant implies that the Turkish context produces particularly entrenched forms of psycho-emotional disablism.

## **DISABILITY RIGHTS AND IL**

Finally, Leyla’s case demonstrates the potential for the philosophy of IL and PA to radically transform the lives of disabled women in Turkey, but in ways that are closely circumscribed by culture and welfare structures. Having the means to pay for PA is the most important factor in enabling disabled people to take risks and to assert choices in their everyday lives in ways non-disabled people take for granted (Morris 1994). In this context, the failure of the state to fund services that enable choice and control not only worsen quality of life, but also, in fostering dependence, undermines civil and human rights. Turkey’s social policy arrangement is itself dependent upon family members, typically female family members, to fill the void left by the state. Other European countries have witnessed the effect of a more prominent rights-based discourse in this area, which has seen informal care become increasingly politically incorrect, if no less central to policy arrangements in practice (Grassman, Whitaker & Larsson 2009). The potential of PA in Turkey is dependent, therefore, upon whether social policy reforms proceed along the path of ‘sacred familialism’ (Akkan 2018) or whether this model may be challenged and made somewhat more profane by the heretofore frustrated rights-based discourse.

## **CONCLUSION**

The way support is conceived, funded and administered determines whether the rights of disabled people are realised or denied. This article explores disability, care and independent living in the hitherto neglected context of Turkey. In this context, cultural and political economies of care are key to understanding the experience of support relationships and independent living: the stark deficit of support within the Turkish state, and the deeply gendered structuring of care, interrelate in ways that limit choice and control. Rights-based approaches to welfare—involving direct payments, personal assistance and an overarching philosophy of IL—have international relevance and the potential to counter cultural and political barriers to independent living. Despite this, it is also vital that scholarly attention is paid to diverse geographies of care so that the aforementioned concepts and policy responses may be tailored in ways that are sympathetic to local social, cultural and political conditions.

## **DATA ACCESSIBILITY STATEMENT**

Research data are not shared due to privacy/ethical restrictions.

Ethics approval was given by Koç University on 25.6.2019 (nr. 2019.200.IRB3.115). Written informed consent was obtained from all participants.

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## COMPETING INTERESTS

The authors have no competing interests to declare.

## AUTHOR CONTRIBUTIONS

Both authors made substantial contributions to the conception of the work and the analysis of data. Both authors revised the work critically for important intellectual content. Interviews were conducted by Dikmen Bezmez.

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