‘NOT-SO-USUAL FAMILIES’: OVERLAPS AND DIVERGENCES IN THE PRACTICES OF CARE WITHIN DISABLED AND SAME-SEX FAMILIES

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This article draws on two qualitative studies on family care conducted in the US and the UK (between 2006 and 2008 the first one and between 2008 and 2011 the second one). It highlights convergences and divergences in the care practices of disabled and same-sex families, and illustrates the importance of shedding light on both the ‘bright’ and ‘dark’ sides of care. Adding a focus on different kinds of carers is not only important theoretically—to fill the gaps—but also strategically—to increase equality. Since difference and inequality co-determine one another, and since heterosexism and ableism will undoubtedly continue, the inclusion of diverse subjects into the discourse on ‘care’, the contextualization of care within situated interaction (Ridgeway and Correll, 2000), and the accent on the positive/energizing aspects of care might be the most effective way not only to achieve greater care related equality but also to increase the symbolic importance that people attach to this crucial social phenomenon.

INTRODUCTION

There are at least three main reasons that make care a crucial territory of inquiry. First, care is a universal experience and a familiar phenomenon to everybody. All of us have provided help to or received a helping hand from others; many of us are most likely going to provide care to significant others in the future. Secondly, due to the ongoing changes in family structures, working patterns, demographic trends, and social security systems, the problems of providing care in flexible and responsive ways are becoming increasingly important (Casper and Bianchi, 2002; Coontz, 2000). And thirdly, at present, there is no agreement on how to frame a sociological discourse on this phenomenon (Pratesi, 2008).
The complex nature of care leaves open several unsolved contradictions, notably those connected with the gendered definition of private and public spheres. Many arguments about care and gender proceed from a misleading dichotomy: women's world of expressiveness and care, on the one hand, and men's world of instrumentality and rationality, on the other (Zelizer, 2005). Such arguments perpetuate a confusing separation if not hostility between the two worlds of sentiment and rationality.

The composite nature of care has been central to an 'ethic of care' discourse developed by several care theorists in the last twenty-five years, and notably in the contributions of Gilligan (1982), Noddings (1984), Tronto (1994) and Held (2006). These scholars have underlined the emotional components of informal/family care (unpaid care) and their implications in terms of gender inequality. However, the crucial role of emotions in informal care still needs to be further clarified, particularly in the light of the role played by 'not-so-usual' carers, including those in disabled and same-sex families.

In this article we will expand on the existing contributions on the ethic of care by referring to those approaches of the sociology of emotion addressing the emotional mechanisms through which social structures are interactionally and situationally reproduced (Kemper, 1990; Gordon, 1990; Collins, 1990, 1993, 2004; Katz 1999; Barbalet, 2001; Scheff, 1990; Turner, 2000; Hammond, 1990). More specifically, we will refer to Collin's theory of Interaction Ritual Chains (2004), according to which the essential mechanism holding society together is emotional rather than cognitive.

This article underscores the necessity to overcome the strict separation between different disciplines and theoretical borders by shedding light on the lived experience of 'usual' carers and on the ways this experience is kept invisible in current literature on care. In doing that, it will also shed light on the less explored aspects of care: those grey areas in which the borders between care perceived as a burden and care perceived as a self-empowering and energizing experience become blurred (Pratesi, 2011). It draws on two qualitative studies, the first one conducted in America and the second one in the UK.

The aim of the first study was building up a 360° phenomenology of informal care, that is, care work carried out at no pay by relatives or friends in private and non-professional settings. More specifically, the study explored the care experiences of 80 carers/parents living in the Philadelphia urban and suburban areas and diversifed by gender, sexual orientation, marital status and type of care. The second study is ongoing in the north of England 'Does Every Child Matter, post-Blair? The interconnections of disabled childhoods' (Economic and Social Research Council). The aim of the study is to explore what it means to be a disabled child in England. The participants in the study include children and young people, their parents/carers and professionals. 'Care' has emerged as a key theme within the analysis dominating parents’/carers’ accounts of their experiences of living in a disabled family.

Emotions are a key element in understanding the mechanisms through which dynamics of inclusion or exclusion and social inequality are interactionally and situationally constructed and/or challenged, and that informal care is a strategic site to analyse such mechanisms. Our objective is analyzing a broader, more inclusive phenomenology of care, which includes subjects (different kinds of carers) and aspects (different kinds of outcomes) of care traditionally excluded from the literature. While the focus is on emotions, the aim is not to individualise carers' responses to their roles but to place them in terms of the social contexts in which they are located and discuss their potential outcomes in terms of status inclusion and/or exclusion.

The Focus on Emotions – Care activities as 'Interaction Ritual Chains'

The focus on emotion is a fundamental component in showing the ambivalences and the grey areas connected with the concept of care and to challenge the assumption that care work is associated with burden and stress and viewed as a result of circumstances or by default. Informal care may be connected with emotional and psychological exhaustion but also with emotional and psychological gratification, reward, self-empowerment, and energizing processes. Nonetheless, there has been considerably less published about the positive aspects of care (Pratesi, 2011).

The Interaction Ritual model (Collins, 2004) allows us to overcome many of the unclear issues left unsolved by current literature on care. Collins argues that emotions are the common denominator of rational action because rationality depends on choosing between different options, the one that is considered the most suitable. Every interaction generates status and power effects, and one of the primary goods of a successful interaction is the feeling of solidarity with a group: a sense of status membership or status inclusion.
Collins describes this sense of status membership in terms of emotional energy, which is similar to the psychological concept of “drive” but with a specific social orientation: it is a long-lasting emotion that builds up across situations and makes individuals initiate or fail to instigate interactions; it is a feeling of confidence and enthusiasm for social interaction (Collins, 2004, 108). Emotional energy is thus both the ingredient and the outcome of the interaction. People’s choices, behaviours, and decisions regarding daily-life issues are in fact based on the emotional outcomes and inputs. And people’s chance to gain or lose emotional energy is strongly affected by their perceived sense of status inclusion or exclusion.

Privilege, power, and status are not “simply a result of unequal material and cultural resources. It is a flow of emotional energy across situations that makes some individuals more impressive, more attractive or dominant; (and puts) other persons in their shadow, narrowing their sources of emotional energy to the alternatives of participating as followers or being relegated passively to the sidelines” (Collins, 2004, xiii). Thus, in Collins’ model, the level of emotional energy becomes a sensitive indicator of social position. In other words, we can also think about inequality or social stratification as an unequal distribution of emotional energy rather than solely as unequal distribution of material resources or social positions. Along with that, we can empirically visualize inequality through a careful analysis of how emotional stratification is enacted in micro-situations.

Inclusion/Exclusion – Feeling Entitled to Care or to be Taken Care of

Care and parenthood can be lived by everybody as experiences of both status inclusion and exclusion, independent of people’s sex, physical condition, or sexual orientation. One belongs to the community of “parents” and consequently he/she can feel excluded from other groups or communities, such as, for instance, the groups of friends with different life styles or the community of successful colleagues who are mostly career-oriented and whose résumés are more brilliant, and so on and so forth. Yet, parents of disabled children as well as gay/lesbian parents can experience care activities as sites of status exclusion in a more prescriptive and rigid way than other parents. In fact, the image of the nuclear, able-bodied family still provides a powerful interpretive template to cast in people’s minds a series of generalized others with whom people engage in internal conversations or encounters.

The sense of status membership or status inclusion can be affected for parents of disabled children by ableism and compulsory able-bodiedness (Campbell, 2009). The sense of status membership can be affected for gay/lesbian parents because of the perceived normativity of the nuclear family and because of heteronormativity (Inghraham, 2005). The perceived failure to achieve status membership can have negative effects, involving negative feelings such as pain, anxiety, concern, fear, and depression. Yet, it can also produce the premises for social change.

On the one hand, parents’ experience suggests that status exclusion can be emotional energy-draining, with long-term negative consequences in terms of social inequality. On the other hand, status exclusion can push people to look for alternative sources of emotional energy, producing, in the long run, a gain in the stocks of emotional energy and reversing, this way, the outcomes in terms of emotional stratification.

The exclusion experienced in certain contexts can be compensated by means of the inclusion in other contexts or group affiliations.

Thus, for instance, the ‘non-fitting’ feeling of the single mother or by the mother of disabled child (emotionally draining) can be compensated by the realization of being able to manage a complex set of multi-task activities against all odds all (emotionally energizing); the status exclusion experienced by a gay parent or parent of a disabled child (draining) can be amply compensated by the creation of a parallel network of gay or straight parents and friends, or other parents of disabled children, the ‘family they choose’ (energizing), which might be seen as a sort of transitional buffer to mitigate the effects of a largely heterosexual, heterosexist and ableist world.

For every kind of carers, independent of their marital status, their sexual orientation and independent of the physical/psychological condition of their children, the sense of exclusion from the community of ‘successful caregivers’ (draining) might push one to work hard and compensate it through the inclusion in the community of ‘successful colleagues’. On the other hand, the temporary or persisting dissatisfaction with one’s professional situation and the consequent status exclusion from the community of ‘successful colleagues’ (draining) can be compensated by a gratifying care activity and responsibility, when this last is acknowledged and valued by others (energizing). In this article we provide some key insights of how these issues intertwine in the practices and lived experiences of parental care of same-sex families and disabled families. Before doing that, we need to describe briefly methods and samples.
METHODS

The data of the American study drew on several methods: semi-structured in-depth interviews, diaries, participant observation, online conversations with and between gay parents, key-informant interviews, and secondary sources about informal care and gay parenthood collected from adoption agencies, newspapers, and the web. All these methods have substantiated the critical interpretive inquiry here illustrated (Denzin, 2001; Smith, 2004; Smith, Flowers, and Osborn, 1997), which is based on the thorough analysis of the interview transcripts and the use of a constant comparative method and analytic induction.

The comparative method means that the qualitative researcher should always proceed through the continual comparisons within and across cases to test out a provisional hypothesis; and it also implies actively seeking out and, addressing deviant cases. Analytic induction refers to a systematic examination in qualitative analysis of similarities between various social phenomena to develop concepts or ideas; it is a way of building explanations by constructing and testing a set of causal links between events, actions etc. in one case and the iterative extension of this to further cases (Denzin, 2001). Within this context, credibility, rather than validity in the dogmatic sense in which it is often proposed, becomes the criterion to assess the persuasiveness of the analyses developed in this kind of qualitative work (Becker, 2001). Credibility is satisfied by detailing each of the emerging patterns and by giving examples of how, where, and in what circumstances they take place with reference to the particular experiences of each participant.

The 80 respondents of the American study were mostly living in the Philadelphia urban and suburban areas. They were different in terms of gender, sexual orientation, and marital status. Both child care and elderly care were included in this study, although parental care is the main kind of informal care we explore in this work. The sample included (42) gay/lesbian carers not only because they have been thus far excluded from the conceptual category of ‘normal’ carers and from ‘normal’ research on informal care, but also because they represented a key-subject to visualize the less explored rationales of care and the crucial role of emotion in the reproduction of social inequality.

The UK study drew on a range of methods and instruments too: narrative interviews with parents/carers of disabled children; interviews (using multiple methods including videos, art work and photography) with disabled children and young people; focus groups with professionals and ethnographic encounters in children and families social worlds. The data presented here is derived primarily from interviews with parents and carers. The interviews were open-ended and covered a range of issues related to the families' experiences of health, social care, education and leisure. However, care was a key theme within the narratives.

In the course of the analysis of the interviews, we visited and revisited the data from all the participants, searching for themes (Snow et al, 2004). While attentive to emergent themes in the data, the analysis we present here is informed by (i) a focus on care; (ii) an understanding of the impact of ableism (Campbell, 2009) on aspects of care.

The arguments we will outline about the ‘not-so-usual-families’ navigating their emotional experience of parental care in the aforementioned studies should be viewed in context and their limitations noted. Producing readable linear narratives out of complex social realities is one of the problems shared by all qualitative researchers. Nevertheless, the credibility of our findings is solidly grounded in the participants’ local, contextual and authentic experience of the phenomenon studied, in the multiple methods and tools used, and in the thorough, systematic analysis of the interview transcripts and the ethnographic data. Pseudonyms were used in the quotes discussed in the following analysis.

FINDINGS

Since our objective is analyzing a more inclusive phenomenology of care, in the following section we examine what we might call the dark sides of care or the draining aspects of care. Under this broad category we include a comprehensive group of sub-themes more or less directly related to care (such as sickness, social isolation, care as a socially devalued phenomenon, gender dynamics, the stigma connected to disability and/or sexual orientation and the commodification of care) that can make care a particularly challenging experience. More specifically, we discuss what are (or might be) the conditions under which care becomes the potential site for unsuccessful and emotionally draining interaction rituals.

This section counterbalances the section devoted to the bright sides of care or the energizing aspects of care, in which we will describe instead the unexplored potentialities of care as an emotional energy producer or enhancer. As we shall see, even in the darkest aspects of the phenomenology of care there is room for unanticipated glimpses of light;
and the motivational strengths and abilities to cope with the draining aspects of care that our carers prove to possess, represent an additional confirmation of its concealed and overlooked energizing power.

THE “DRAINING ASPECTS OF CARE” – CARE AS A BURDEN

One of the first not-so-trivial truisms about childcare is that, unlike a partner, a child is forever. You cannot so easily divorce or legally separate yourself from your childcare responsibilities. Once you are a parent, you remain a parent forever and, during the first years, almost 24 hours a day, as the following dad, Morgan, reminds us:

(...) But I mean it’s still the case that, you know, one of the things with Henry is that he’s always there. So I mean it’s not like 24 hours a day but it’s, you know, like 12 hours every day and mostly he’s awake when you’re awake, I mean there’s a lot of responsibility (...)

By the same token, Emily underscores how the draining aspects of 24-hours-a-day care may involve not only menial chores or tasks, but also the thinking process itself:

Yes, he drains a lot of my time and my thoughts. I think of him when he’s not around.

For parents of disabled children, the 24-hours-a-day nature of care is combined with a sense that their care is on-going and, perhaps, life long. While all parents may experience ‘burdensome’ aspects of care, parents of ‘typically’ developing children usually expect their care pathways will change as their children grow up, whereas parents of disabled children sometimes feel that their caring role will be static and continue to be demanding:

I mean, you know, that makes it really, really difficult. And I think that they [parents of non-disabled children], you know, they don’t seem to understand. It doesn’t change does it? It’s like, you expect with, you know, a five year old starting school, of course you expect to be there ‘til the moment they go in and be there the moment they come out, but when your child gets to 13, for the most part it’s, “There’s your key, I’ll be an hour, blah, blah, blah,” and you [parents of disabled children] can’t do it.

One of the key issues connected to childcare is the internal struggle between the idea that children come first and the necessity to reconcile this idea with a wide range of tasks, responsibilities, but also leisure activities. One commonly shared faulty assumption is that the world can be divided into two main categories: those for whom having or not having kids is a ‘natural’ consequence of their life choices and those for whom procreative options are not contemplated at all. Such a misleading assumption hides the wide range of varieties and possibilities of those—the majority—who lie in between. It is probably not by chance that both the rhetoric of parenthood as a sort of naturally forthcoming gift blessing heterosexual couples and the rhetoric connected with the idea of the ‘feminine mystique’ (Friedan, 1963) are more often challenged by lesbian mothers (quintessentially ‘mothers by choice’) than by any other parent. This is, for example, the case of Allison, a bouncy and forthright teacher who points her finger at the unspoken ambivalence about parenthood typical of most parents:

...No, I don’t mean that it’s important to do it or not do it, I think some people want to, some don’t. And I wasn’t sure I wanted to have children, I wasn’t sure at all because I didn’t know if I wanted to give up my life, you know. Because the baby has to come first for many years. And I’m still ambivalent about that many times. But I think most everyone is. (...) Jane, the mother of three disabled children, also expresses ambivalence about her caring role:

Everybody else goes home at the end of the day, everybody else if they decide to leave this job, they can go somewhere else. I am the only person that has been with the children all the way through.

Jane says that it was impossible to find childcare for her children and, thus, impossible for her to work. The family’s dependence on benefits puts a huge strain on Jane as she struggles to manage a tight budget. Jane is also a single parent, and the draining aspects of care are reinforced by that. The condition of single parents creates additional penalty to the typical constraints every working carer meets. Care related constraints are extremely amplified in the case of single parents since they cannot easily rely on substitutes or secondary carers.

In this respect, the story of Julia is quite exceptional, but not as unusual as one might think. Julia is a teacher in a school for children with ‘disabilities and learning difficulties’. At the time of her unplanned pregnancy, she was a social worker in Florida but the agency for which she was working, as she tells me, “lost its funding from the Federal Government, so they just closed their doors, and everybody was laid off”
It was a Friday afternoon meeting and... the doors are now closed, come on Monday and clean out your desks kind of a situation. So at the time I was eight months pregnant, so I had to apply for unemployment and then I lost my maternity pay after that had happened, and I lost my benefits. So I had to pay COBRA, which is an outside service that will provide you medical benefits at a very costly amount. Where my benefits had been paid for by my employer, now I was paying for the benefits, which I had no choice because I was eight months pregnant and I was about to embark on a hospital visit to deliver.

The specificities connected to the fact of being single make single parents, and especially single mothers, particularly exposed to the risk of economic and emotional impoverishment; this is particularly true when such specificities are coupled with a culture of self-sufficiency. In fact, another common characteristic of many of our respondents is that they tend to be self-sufficient and to describe their attitude of not asking or not relying on other persons as a personal trait, or as ‘a personal thing’.

When talking about the dark sides of care, we cannot leave out the several ways in which Western capitalist societies devalue care. Western societies seem to operate through a sort of collective denial when it comes to care. Among our respondents, there are several arguments against this collective denial that is fostered by current politics and institutions. For instance, there are those who underline the gap between what we know and we do about childcare and what we (don’t) know and (don’t) do about elderly care. Some talk about the necessity to ‘educate’ and prepare people on how to deal with parents or relatives who are getting older and dependent. Ruth accuses here the typical Western youth-oriented attitude that tends to skip altogether both childcare and elderly care related issues:

I think that our society falls short with this because we’re not really, we’re a society that cares about youth, not children and not the elderly. (...) we really fall short when it comes to caring for the aged. (...) And if people haven’t gone through it, they have no clue.

Susan, a mother of a child with a life-limiting impairment, talks here about the devalued nature of the care she did when she thinks about what work opportunities would be available to her after her son died:

[The future] is very bleak... Do you go down to the supermarket and say well actually I’ve been looking after a disabled son for 19 years. He’s gone away now and I’m here, I mean, I don’t want to work in ASDA [supermarket]!
Another example: when heterosexual prospective adopters resort to adoption agencies they are not exposed to the dreadful and worrisome stories such as the one exemplified in Omar's and Curtis' story. Stories like this, unfortunately, are not as rare as one might think, and particularly gay men are subjected to these kinds of oblique bargains or other forms of negotiations. Because of a mistake caused by the adoption agency, Omar and Curtis were offered the following hideous ‘last-minute deal':

So we talked to this one broker, she called me and she said I've got a perfect situation for you, the woman's pregnant, she's had a child before, there's no issue with that, she's Caucasian, the father's Caucasian, blah, blah, blah. And it was like great, what do we, you know, we kept talking. She said well, I do have to tell you that there's a chance that the father's African American. I was like, what do you mean? She said well, her partner's Caucasian but it was a crazy weekend and she said there is a chance that the father's black, but don't worry, if it ends up being a half black child, then I'll cut my rate for you and I'll do it for half price. I hung up the phone and I called Omar and I was like, I can't do this, this is disgusting. I'm like I refuse to do this anymore. So we switched pretty much that day.

Omar and Curtis are not an isolated case. Furthermore, the commodification of care is not the only issue at stake and it can take several forms. Sometimes, with domestic adoption, American prospective gay adopters are offered to adopt children with serious health problems, physical disabilities or psychological disorders to increase their chances to be selected from the agency (see also Strah, 2003).

The contentious nature of the commodification of care is also verified in the lives of English disabled children. Sadly, disabled children put up for adoption in England are often presented as ‘damaged goods'. Be My Parent magazine is used to advertise ‘hard to place' children to prospective adopters. Pictures of disabled children are accompanied by a list of their impairments and associated behaviour, with the offer the financial compensation of disability benefits to the parents willing to ‘take them on'.

All these aspects compose the picture of what we called the ‘dark sides' of care and, in order to give the reader a more inclusive and extensive understanding of the phenomenology of care, this picture must be integrated and combined with the other and less explored picture, that is the one devoted to the bright sides of care or the energizing aspects of care. In the following section we will therefore navigate through another astonishing aspect of the phenomenology of care, which, we claim, represents one of its fundamental components: the overlooked potentialities of care as a source of Emotional Energy.

THE “ENERGIZING ASPECTS OF CARE”–CARE AS A SOURCE OF EMOTIONAL ENERGY

The exploration of the dark sides of care reveals how, even in its most draining aspects, care seems to make people find their “second wind,” as William James (1913) called it: an unanticipated strength and energy that allow carers to handle care related challenges and difficulties. Care does not necessarily make people less active or productive. Not always, at least, and not under all circumstances. More than what we are willing to acknowledge, being caring also means being energetic and productive. The analysis of the interviewees’ accounts both in the US and the UK shows that, under certain conditions, care activities and a caring attitude make people more efficient and increase their capacities to get more things done in a more focused way.

The analysis of the symbolic implications and meanings of care in the entire ecology of people’s lives reveals the existence of new unexpected and unexplored rationales of care, which can be radically reinterpreted in light of the Interaction Ritual model (Collins, 2004) and with the inclusion of gay parents and parents of disabled children. One of these less visible rationales is the energizing and empowering nature of care, that is, an extra layer of energy that not only helps carers to avoid burnout, but also to make up for and/or to counterbalance their sense of status exclusion from other contexts or realities.

The energizing nature of care is aptly illustrated in the following passage, where Jason remembers the period when he was finishing his dissertation, teaching full-time, and being a dad:

J: It was a hellish couple of years. But at the same time I think being a dad helped me to balance out some of that. I mean I think if I would not have been a dad and would have just been trying to finish the dissertation while teaching full-time, I think I would have driven myself crazy. (....) Because for me parenting really gives me energy.

I: In what sense?

J: I feel, well, after – my kids make me feel good about myself and academia doesn’t always make me feel good about myself. (laughter) In fact, growing up, neither of my – I’ve always felt a little insecure in academia just cause my, neither of my parents were college graduates and this whole thing is very – my parents were pig farmers and so I’ve
always felt very insecure. But being, I mean there's a lot, as I said before, there's a lot of insecurity in parenting but it just makes you feel good about who you are as a person.

Several other interviewees point to the concept of the increased energy and efficiency connected to the necessity to find a balance between work and care. Byron, a financial advisor who decided to have a child with his close (lesbian) friend, is one of them. Byron and the biological mother of his son live in separate homes and worlds, but they share equally childcare responsibilities. This is Byron's account of increased energy and efficiency:

I: Would you renounce something in term of career or job or your personal...

B: Well, this is a good question for me because I don't have to renounce anything, you know.

I: Well, if you had, probably if you had additional care responsibilities...

B: Maybe, but I could still manage to do my job. You know, I became extremely efficient after the baby was born in doing the work with 30 or 40 percent less time and I still managed to do it all.

I: Really? That's another information that you didn't give me.

B: Absolutely, mm, hmm. Because time had many more things packed into it so I had to become more efficient - a rather easy thing to do. If you want someone to do something, you pick someone who is busy to make sure it gets done, you know.

I: So the more you are busy...

B: The more productive you become, absolutely.

While parenting disabled children is often characterized as draining and burdensome, recent analyses of the lives of disabled families have offered more positive interpretations of parenting a disabled child (McLaughlin et al. 2008). Indeed, the energizing and productive aspects of care are certainly evident in the lives of parents of disabled children, as it is also emerging from the following accounts. Kate describes here, with a sort of fatalistic and positive attitude ("things happen for a reason") her coincidental 'career change':

You know, at the end of the day, they say things happen for a reason and I used to think, yeah maybe so. And the weirdest thing was I was thinking about changing my career and what freaked me out I was thinking of doing work with children and I was thinking of going and working with Childline. Hence, me I've had this baby and I've got a career with children now, through him.

Jane highlights in the following quote the enormous pedagogic value, from an existential point of view, of her caring for her disabled son:

So although it's been very upsetting - it's been really distressing at times - it's been a massive learning curve, and it's taught me a lot about myself.

This sense of meaningful perspective and experience is also shared by Susan:

I have got a friend and she will moan about the stupidest of things and I think well I'm luckier than them, my life is fuller and it might be fuller of the negatives, but look at my kids they are going to grow up into much nicer adults than your kids who moan cos they haven't gone swimming on Saturday or something like that. So I feel, it feels a bit cheesy to say 'blessed' or something like that no I feel that I am a much better, much more patient understanding person than they are and I'm luckier than they are in that respect. And that is why it was so frustrating about my mum and my sister they were unable to see that it was them that was lacking.

Susan explains the positive and, perhaps, transformative aspects of care which are productive and energizing. Susan's constant interrogating herself about her 'unusual' care experience has led her to reject 'normal' and 'normalizing' concepts of care and parenting. Her exclusion from the category of 'entitled/legitimate' parents has been the catalyst for her productive and positive engagement with care.

CONCLUSIVE REMARKS

The complex nature of care, at the intersection between informal communities and formal organizations, leaves open several unsolved contradictions and makes of care a phenomenon still problematic and in need of further specification. This is because care transcends typical distinctions between work and leisure, public and private, and productive and reproductive relations. We often talk about the right to receive care and the duty to provide care. We often discuss the gendered costs of care. We rarely ponder, yet, on the lived experience of 'unusual' or 'not-so-usual' carers and on the ways this experience is kept invisible in current literature on care.

On the one hand, there is the official arena of discussion for care and its gender related issues where scholars from different disciplines discuss the balance between career/work and care/family, in a gender perspective. On the other hand, there is a parallel and invisible setting of all those...
caregivers, such as same-sex parents and parents of disabled children, for whom several other issues are at stake beyond gender and beyond career and family balance. Among them, notably, the issue of being acknowledged and valued as legitimate/entitled caregivers not ‘in spite’ of their specific and atypical form of care responsibility or because of their sexual orientation, but regardless of them.

Thus, for all these carers who do not have full social visibility, entitlement, or acknowledgement, their ‘not-so-usual’ experience of care might certainly go side by side with the experience of care of what academic research and policy makers typically tend to address, that is, the experience of the ‘usual’ carers; but it might also embody a different agenda which is not necessarily aligned with the agenda and the interests of other carers. There cannot be a universal manifesto for all different kinds of carers, there will never be. Yet, what can be hoped for is the eradication of a deceiving sense of competition between the different kinds of carers, particularly in a situation when resources for care are scarce and are going to be more so in the future.

The two studies described here show how the meanings of care and its unexplored rationales can be drastically reinterpreted in light of the Interaction Ritual model (Collins, 2004) and with the inclusion of gay parents and parents of disabled children. They are based on the hypothesis that emotions are a key element to understand the mechanisms through which dynamics of inclusion or exclusion and social inequality are contextually constructed or challenged, and that informal care is a strategic site to analyse such mechanisms. Our objective is analyzing a broader, more inclusive phenomenology of care, which includes subjects (different kinds of carers) and aspects (different kinds of outcomes) of care traditionally excluded from the literature. The focus on emotion is a fundamental component in showing the ambivalences and the grey areas connected with the concept of care and to challenge the assumption that care work is associated with burden and stress and viewed as a result of circumstances or by default.

By going beyond the overtones of grand theories, our constructionist and interactionist approach highlights convergences and divergences in the care practices of disabled and same-sex families and illustrates the importance of shedding light on both the ‘bright’ and ‘dark’ sides of care. Relocating ‘care’ in situated interaction, while shedding light on its latent purposes and clarifying the central role emotions play in the reproduction of inequality allows us to address many of the unsolved theoretical issues transforming them into empirical ones, analyzed in specific contexts (Ridgeway and Correll, 2000). Adding a focus on different kinds of carers is not only important theoretically—to fill the gaps—but also strategically—to increase equality. Since difference and inequality co-determine one another, and since heterosexism and ableism will undoubtedly continue, the inclusion of ‘not-so-usual families’ into the discourse on ‘care’ and the accent on the positive/energizing aspects of care might be the most effective way not only to reduce the inequality connected to care but also, paradoxically, to increase the symbolic importance and value people attach to this crucial social phenomenon.

Notes

1. “Paradoxically, by perpetuating the myth of inescapable divisions and battles between the worlds of sentiment and rationality and, of market and domesticity, hostile worlds arguments divert us from real solutions. [...] To the extent that normative discussions assume the existence of separate spheres and their mutual corruption at point of contact, those normative programs will fail to accomplish their announced objectives. It therefore matters to get the interaction of intimacy and economic activity right. Looking at coupling, care, and households we did not find separate worlds of economy and sentiment, nor did we see markets everywhere. Instead, we have observed crosscutting, differentiated ties that connect people with each other. We witnessed people investing energy and ingenuity in marking differences among their relations to each other and regularly including economic transactions in those intimate relations. None of us, we have seen, lives in segregated spheres with unbreachable barriers between our personal relations and our economic ties” (Zelizer, 2005:297-298).

2. The first research presented in this article is focused on one specific kind of informal care (childcare) and one specific group carers (gay/lesbian parents). In another paper exploring the emotional dynamics revolving around care other kinds of care and carers are also addressed. See Pratesi, 2011.

3. David Cameron’s six year old son, who had cerebral palsy and epilepsy, died in February 2009. David Cameron is the leader of the UK Conservative party and Prime Minister since 2010.

4. Be My Parent magazine in England for prospective adoptive parents. Typically, the children included in the magazine are ‘hard to place’ children who are described as having a range of ‘difficulties’.

References


