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Negotiating Power Inequities in Caregiving Relationships

Pamela J. Cushing

Abstract

Moral philosophers have debated whether power asymmetry precludes relational mutuality. Some ethicists deliberate over the delicacies of such imbalances in relations between patients and healers. Caregivers, however, know that in practice, relationships can and do develop, and can enrich the care experience for the client and staff. Emergent client-centred caregiving ideologies furthermore request a level of relational engagement by caregivers with clients. These relationships can be fruitful but are difficult to navigate: they tend to blur ostensibly clear professional boundaries, and complicate the traditional, one-way exercise of power Here, I demonstrate that the positive outcomes of working towards mutuality in care warrant the extra effort required. The anthropological research for this paper was conducted in L'Arche residential care homes for people with developmental disabilities. I define core elements of mutual relationships in L'Arche, and I use stories from everyday life to illustrate these caregivers' power-sharing strategies and tactics.

The practice of labelling and segregating people with intellectual disabilities, and their itinerant, intractable stigma have long been questioned. Emergent research also challenges the meaning of the definition of disability itself (Roeher Institute, 1996), noting the continuing social exclusion, abuse and maltreatment of people with intellectual disabilities, in spite of the hopeful rhetoric of normalization and integration (Lunsky, 2002; Sobsey, 1994). Issues such as these afflict many marginalized groups and are partly produced because those with power lack a sense of commonality with those without it. Amidst this loss of connectedness, though, people do manage, under certain conditions, to build fruitful relationships across difference, disability, and inequality. Here I explore an approach to encouraging caregivers to be open to such relationships that have unfolded over time in L'Arche. I discuss definitions and cases.

Background and Method

L'Arche communities (a network of local homes) began forming in the late 1960s in France and Canada, and quickly grew internationally. Jean Vanier founded what became the federation by opening homes for people who have disabilities so that they could leave the institutions. It operates with a social justice paradigm and a humanitarian spirit.

Although L'Arche communities are in some ways similar to a group home format, there are three key features that distinguish them: faith, co-habitation, and a relational ethic of care. L'Arche is a spiritually-based, network of residential caregiving communities in which people with developmental disabilities and their caregivers share the home together. Although Christian in origin, in Canada L'Arche is interfaith. In contrast to the strict emphasis on independent living in mainstream care, L'Arche accents the quality of people's relationships and sense of belonging. L'Arche holds that people with intellectual disabilities have gifts to offer society and those who care for them. My aim is to translate useful L'Arche principles and practices for mainstream, secular care scenarios.

This paper is based on four years of primary and secondary research on L'Arche communities across Canada, including one year of full-time fieldwork as a live-in participant observer and caregiver. As a participant observer, I worked part-time as an assistant in one home, and participated in meetings, social events, prayer services, and meals in homes in eight communities. I also conducted surveys and over 80 interviews with current and former assistants. The ethnography examined how L'Arche functions as a distinct sub-cultural system within the disability care field.

Evolving Mutual Relations

While promoting mutual relationships and shared decision-making have always been part of the L'Arche approach (Vanier, 1995), what exactly that means has evolved over time and through practice. Vanier concedes that although he ascribed to the biblical belief in the prophetic gifts of the marginalized, in practice, he and the founding assistants were initially guided mainly by a traditional charitable paradigm of the abled assisting people with disabilities through deinstitutionalization. The latter paradigm is not unkind in intent, but eventually Vanier and other assistants saw how it disregards the value that both types of people in a caregiving dyad bring to the interaction.

With more time and experience, Vanier came to realize that the deeper gift of L'Arche went beyond the physics of care. The scenario they created of radical, intimate exposure to difference and disability brought with it new and vital possibilities to break down barriers and get to know people with disabilities as fellow beings, not merely as objects of care. In that spirit, techniques of normalization, control, and behaviour management were adjusted to accommodate greater acceptance of people just as they are, and relationships with them on their terms. Training new caregivers in how to follow this and to get underneath difference and disability is now a major part of the work of L'Arche as an agent of cultural change (Cushing, 2003).

Learning to Value Social Diversity

Although Canadians generally claim a desire to be tolerant and accepting of difference, this is always more difficult in practice than in theory (Geertz, 1994). Acceptance is even more challenging to enact when confronted with someone who is different in a way that is shrouded in stigma. People with disabilities express the awkwardness that can arise in interactions with the unimpaired, who often simply do not know how to avoid a deficit-based conception of disability (Murphy, 1990). In L'Arche, the idea is to give people a chance to get to know one another, and support the possibility for commonality to surface through training assistants to problematize their accepted beliefs about disability and care. Below is a simple but compelling narrative fragment in which Sam, a 27-year-old assistant of two years, speaks of the change in his outlook on disability and his overall imaginative possibilities. Sam shares his thoughts about getting to know Jeremy.

I like feeling my consciousness changed here [L'Arche]. When I first met Jeremy, there was just a kind of awe for me - no comprehension: he just seemed so different. He can't tell you what he thinks or wants and he can seem so distant. Later I got a bit more comfortable and I caught on to people's subtle communications. I could also find people's oddities (like Jer's yelling) engaging - like I can just let it wash over me as part of life. I am honestly now proud to go to the church in town with Jeremy. I think it is good that we don't just stay at our own chapel, because out there more people can be exposed to his reality; and maybe they'll feel uncomfortable when he yells, but so what? Now I see it as just part of life and I want others to get there too. [Sam, caregiver]

What is at Stake and for Whom?

Although often rewarding, such relationships of mutual influence can simultaneously be quite difficult and there are several barriers that prevent their emergence and longevity. The persistence of negative attitudes and stigma towards people with disabilities means that, unfortunately, neither the public nor most caregivers exhibit much interest in developing genuine relationships with them: research reveals that inadequate relational connections are commonplace (Brown, Raphael & Renwick, 1997; Lunsky, 2002; Lutfiya, 1993). Even if a connection blooms, the relationship is often inherently difficult to sustain, especially without appropriate supports in place (Kittay, 1999; O'Brien & O'Brien, 1993). Finally, funding cuts have led to limited staffing levels and higher time pressures on staff, leaving them little discretionary time for relational interaction. Research from the United States about nurses struggling with reduced staff revealed that positive relations with clients had made the other job hardships bearable (Chambliss, 1996).

My research with L'Arche uncovered many cases of the potential emotional and therapeutic value of cultivating such relations for caregivers as well as people with disabilities. It is especially important to identify and discuss how attending to relational elements can benefit direct caregivers because, ultimately, it is they who must believe in the value of such relations in order for them to work. Moreover, they have the most at stake. Agreeing to engage in emerging, client-centred models of caregiving involves power-sharing, openness, and vulnerability; this entails that caregivers risk certain loss (e.g., in authority) for uncertain gains. This is important given that many caregivers are already undervalued, underpaid, and over-worked (Braddock & Mitchell, 1992; Steinhoffsmith, 1999; Ungerson, 1999).

Negotiating Fairly Across Power Inequities

Mutuality in care also has costs. To illustrate what is at stake for caregivers in pursuing mutuality and power-sharing, I share this story about Frank, an older man in L'Arche with a talent for wood-working. The story is about the inclusive process that was built to preserve and negotiate power-sharing in his relations with caregivers, when he began having challenges with getting to the toilet during the night. The story illustrates the additional work that power-sharing processes can entail for the caregivers, and is noteworthy because they remained committed in spite of this.

The negotiation of power-sharing is often not a dramatic moment, but rather transpires over long periods of time and in small, everyday kinds of agreements. In L'Arche a small group of people are usually involved in providing information and supporting a person with disabilities to make safe decisions so as to minimize interventions. This voluntary power-sharing approach was used for almost a year with Frank. I was struck by the team's commitment to investing significant time (in discussions, appointments, and plan follow-through) to find a solution that "honoured" Frank, rather than rushing to an easier, control-based option, which would certainly have saved them time, work, and worry.

When a medical solution was ruled out by doctors, and Frank rejected the protective briefs option, other conversations were initiated with the team and a therapist to explore what underlying feelings or stresses might be triggering his incontinence. A range of stress-reduction solutions were developed and executed, but did not resolve the problem. Although Frank also initially opted to have the over-night relief person wake him up at intervals, he frequently declined to go, even when he needed to. His choices left him uncomfortable, embarrassed, and increasingly confused. It is also not hard to imagine the extra cleaning this produced for the assistants.

Still, the assistants continued like this for the year, supporting each other to stay committed to sharing the authority and decision with Frank. Eventually, Frank chose to wear night-briefs. This negotiation process was felt by all to be fruitful in that it yielded dignity and respect to Frank, who was able to continue in his existing amicable relations with caregivers in the home because trust and cooperation were preserved.

Dimensions of Mutuality in Caregiving Relations

In this section, I present what I observed to be the tacit guiding principles of these mutual relations in L'Arche. Mutuality is a condition of mutual respect, understanding, and support that can be cultivated between two people in a relationship, and the relationship is fruitful, or growthful for both people. Steinhoffsmith (1999) wrote; "Normative mutuality is a relation in which all who participate bring out the best in each other and help each other to live fully" (p.21). Mutuality in relations with unequal or instrumental dimensions, such as caregiving, however, add another layer of complexity. Professional ethics and obligations play complicating roles in how and why the relation develops, and what the limits of the relationship are. Six principles of mutuality in L'Arche are:

1. General and particular

L'Arche holds that effective mutuality is both general and particular. It is promoted as a general way to approach all relationships (including but not limited to, caregiving) in a spirit of openness and respect, especially in regards to reaching across difference and inequality. However, mutuality is most effectively developed or deepened in the particulars of particular relationships. In other words, mutual care means caring for and about a specific, unique person rather than a category of client (see Taylor, 1994).

2. Instrumental relationship

Caregiving relationships are invariably occasioned by the clients' need for assistance from the caregiver. It must therefore be acknowledged that this is always initially and fundamentally an instrumental relationship. Their relation is never free from the inherent imbalance of the instrumental motive, even though their mutual feelings may grow to encompass much more than that.

That inherent imbalance has been the basis of debates in philosophy and ethics about what kind of relationship is possible, and whether it is even ethical or desirable to nurture one. Aristotle, for example, felt that inequality and dependence precluded friendship (Aristotle, 350 BC/1976). Hingsburger (2001), a counsellor, argues against such relations since clients might fear that they have to accept the friendship so as not to jeopardize the quality of care they receive. Clients' freedom does need to be protected; however, in the case of people with intellectual disability who often experience a paucity of informal social contact, it seems illogical and even iatrogenic to prohibit relationships with caregivers. Appropriate monitoring systems can ensure voluntarism and freedom.

3. Process versus outcome

The notion of mutuality in relationships at L'Arche is concerned mainly with the daily process or ongoing, subjective shift of learning to be open to the value of difference (see Pottie, 2001). They are less concerned with idealistic outcomes of perfectly mutual relationships. This contrasts with definitions of mutuality as a euphoric moment of connection (Buber, 1970). Most of the stories that assistants tell informally or formally are about ordinary mutual interactions that are made more meaningful through the assistants' interpretation of them within the L'Arche paradigm.

4. Elements of reciprocity

The terms mutuality and reciprocity both refer to a flow of giving and receiving between parties and are often used interchangeably. They can also refer to systems that attempt to include a wider range of gifts (often intangible) in their notion of exchangeable units (Carruth, Tate, Moffet & Hill, 1997). Interestingly, I found that L'Arche assistants often use a generalized reciprocity script to describe what they do, even though they are paid employees. Although bound by legal, free-market contracts, much of their discourse reflects notions of a gift economy (Mauss, 1954). Caregivers and staff talk about "giving" time, love, or extra effort for residents, as a way of indicating what is given out of care, "over and above" job requirements.

Officially, the caregivers indicate a belief in gratuité, or "giving without counting the cost," but it seems that an imbalance in giving is uncomfortable for all of them. Instead, L'Arche caregivers have inadvertently created an alternative currency for this exchange by revalorizing the gifts inherent in their clients' lives. The lessons learned from their example, or their kindness, become the valued return for what is "given," thereby restoring balance.

5. Solidarity

Caregivers at L'Arche also often describe power-sharing and mutual relations as part of a moral, spiritual, and political project of solidarity with those who are marginalized (see also Spink, 1990). Assistants often describe their desire to make the effort to reach across inequality to cultivate common ground in relationship with others as a way of recognizing and alleviating their disenfranchisement. This kind of solidarity seeks to reverse the reproduction of structural inequality that is typical of normative relations like caregiving.

6. What is not mutuality: The Labour of Care

The political project of solidarity and mutuality should not overshadow the fact that what the caregivers are doing is labour, and needs to be credited as such. Researchers have demonstrated that this work already faces multiple devaluation by being classified as low-skilled, women's, emotional labour. In spite of the potential for relational mutuality, the practice or labour is inherently asymmetrical, and that must be recognized to avoid further undermining the value of the labour of care (Kittay, 1999).

Conclusion

Caregiving relations are indeed a delicate site for negotiating and sharing power and any programs directed to this end must be well considered. These guiding principles and illustrative cases are intended as a tool for such reflections, and as evidence that a relational emphasis can be quite fruitful in tandem with other standard care approaches. Since the field is moving towards greater inclusion of people with intellectual disabilities in life decisions, this model for the development of respect and relational ties moves in the right direction.

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Correspondence

Pamela Cushing
Anthropology Department
Chester New Hall, Room 509
McMaster University
1280 Main St. West
Hamilton, ON, L8S 4L9
cushinpj@mcmaster.ca