

## Forum

# From commodity to community in nursing homes: an impossibility?

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### Introduction

Ever since Erving Goffman (1962) discovered unexpected social bonding and elaborate social networks among the ‘inmates’ of total institutions, researchers and policy makers have used ‘community’ to refer to those very persons (nursing-home residents, in-patients in psychiatric hospitals, and others incarcerated for diverse disabilities) believed to be ‘its principal victims’ (Hazan 1995: 211). The concept ‘community’ was built upon Tönnies’s (1955/1887) concept of *Gemeinschaft*, which depicted homogeneous groups integrated through multiple social linkages and face-to-face relations. By the 1970s, scholars of community studies called into question the conceptual underpinnings and potentially negative implications of the concept. They reframed ‘community’ as a concept that addressed more refined questions concerning locality, and reserved the term for the social networks that reflected group interests and provided symbolic evidence of identity formation or belonging (Davies 2003). Nonetheless, the term retains prominence for the institutions that provide residential care for people with various disabilities.

The term ‘community’, however, has specific features that call into question its relevance for the residents of institutions. The usage is problematic when referring to special-care units of nursing homes for people with cognitive impairments, particularly because of the limited extent to which the residents are involved in developing relationships in these regimented settings and in creating the ‘communities’ of which they are purportedly a part (*cf.* McAllister and Silverman 1999).<sup>1</sup> Given that care in nursing homes and special-care units is commodified, the use and relevance of community in those settings must be called into question.

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This article provides a critical discussion of the use of ‘community’ to describe institutional settings, especially those for cognitively-impaired older people confined to special-care units. After briefly describing the setting and methodology for a larger study, this paper reports the problems that were observed in its usage. It then explores alternative formulations of ‘community’ that challenge the relevance of its application to institutionalised elders. The article concludes by questioning whether community can in fact be realised in commodified institutionalised settings, and suggests some conditions under which it might occur.

### **Background, setting and method**

This article draws from observations made during an intensive 18-month ethnographic study that compared two special-care units for older people with severe behavioural manifestations of dementia. The purpose of the study was to explore the possible meaning of the disturbed behaviours and interactions of elders with others, and it paid particular attention to the contexts in which disturbances occurred, declined or worsened. Drawing from a theoretical framework that regarded behavioural disturbances as possible attempts to communicate needs, desires or problems, the study compared the approach and social organisation of care in the two units and the outcomes for the residents (McLean 2006).

Each unit was part of the same 500-bed continuing-care facility in an urban area on the east coast of the United States. Each housed 40 residents, most of whom were female (82.5%), and their ages ranged from 68 to 99 years (median 87.5). Many residents displayed verbal or physical aggressiveness, public undressing, repetitiveness, and other disturbed behaviour. The units were intermittently noisy from their vocalisations. Most residents had been transferred to the unit from others in the facility after their condition deteriorated; it was very rare to be admitted directly from outside. Because of the units’ reputation for housing very disturbed residents, the administrators and staff had to be very persuasive with a resident’s family members before making a transfer.

The methodology was ethnographic, and used participant observation, detailed recording of observations and informal and semi-structured interviews with staff (from housekeepers to physicians), family members, visitors, and residents.<sup>2</sup> I spent approximately nine months on each unit, and conducted daily observations during the day (7 am to 3 pm) and evening shifts (3 pm to 11 pm), and sometimes overnight. In addition, a daily log of general floor-wide observations was kept and intensive observations of six residents in each unit were conducted serially for one month each, and

documented in a separate log. These residents were selected by the clinical staff for their extremely disruptive behaviours. In association with the observational studies, I attended regular or special meetings convened by clinical and/or administrative staff. One considered how to reduce the noise levels on one of the units. While some staff felt that the noise signalled angst, a supervisor said that the residents needed to remember that 'this is a *community*'. Her comment raised my curiosity and stimulated this examination of the legitimacy or appropriateness of the usage.

### **Problematic usages of 'community' in nursing homes**

The usages of 'community' by the nursing-home staff, and their appeals to residents as presumed members of that community, imported externally-generated notions and lacked any reference to or input from the residents. Their usage carried the implication that the residents should behave responsibly as members of 'the community', but made no reference to their abilities or desires. The constructed obligation totally disregarded the involuntary circumstances of the elders' residence in the nursing home. The motivation for the staff's use of 'community' is not necessarily consonant with the interests of their residents.

#### *Community as a collection of other individuals*

When asking cognitively-impaired residents to minimise disruptive behaviour, such as noisiness (Cohen-Mansfield 2000; Shomaker 1987), nursing home staff often appeal to a resident's responsibility to others in the community. A community, however, cannot be defined solely as a collection of individuals, any more than it can be defined by locality or place (Davies 2003). As pragmatist philosopher John Dewey argued nearly a century ago (Boydston 1976–83: 8),<sup>3</sup> a community is more than a group of people; it entails deliberate engagement by all its members towards a common end, for which they voluntarily adjust their actions (*cf.* Hester 2001: 50–2). While an appeal to moderate one's behaviour in the 'interests of the community' is normally reasonable, most residents of special-care units are too impaired to comprehend the collectivity. Further, except for the few who respond to noisy neighbours with a resounding 'Shut up!', most are too preoccupied with their own problems to voice such concerns.

#### *Community as an idealised marketing device*

Complaints about noise more commonly came from family members, especially of newcomers to the unit. The apparently facile usage of

community under such conditions may be more intentional than meets the eye. The management have to keep units full, and present to prospective client families a sentimental image of the home as congruent – or a continuity – with the past. Such ‘communities’ are generally contrived constructs that inaccurately reflect reality and promote other vested interests; in this context, the financial viability of the nursing home (Hazan 1995). A pressing concern of the administrators of units where families complained was to correct the problem so that they could ‘sell the unit’ to new families. Their various references to an idealised community masked underlying economic considerations. ‘Community’ evoked images of unity and commonality that rarely represented the reality of the residents’ lives.

*Community as institutional rather than resident-generated*

Goffman (1962) showed that forms of self-governance are available to members of some total institutions, however restricted and convoluted. The levels of engagement required to participate even in these restricted forms of self-governance are not usually available, however, to the residents of special-care units. Members of a self-governing community must agree on its practices. The residents of special-care units have too limited reasoning abilities, organisational skills and patience to negotiate their own rules. In fact, if their views and preferences are inferred from their responses to the demands placed upon them, one might see, as suggested astutely by a nurse, ‘a collectivity of shared *anti-rules*’, including no bathing, no early wake-up, and toileting and meals upon request. All these preferences require serious attention, but are unlikely to be met in bureaucratised settings. Inferring rules in this way and revising them to address the preferences of the residents might be *exactly* what is needed to improve the quality of their lives and care. The wider acknowledgement of the residents’ shared preferences might even be the basis of a form of community that is accessible to those with dementia. Far from acknowledging the residents’ common preferences, however, the staff required the residents to conform to community standards and the institution’s expectations of behaviour – a far cry from standards generated by, or inferred from, the residents themselves.

*Community as obligatory behaviour*

The demands on the residents to act with consideration for their neighbours was based on the questionable assumption that they were fully capable, and thus obliged, to recognise the needs of those around them. Such demands are similar to those of other contrived collectives, which are ‘all-too-often settings of a high degree of normative control’ (Hazan

1995: 212). As bio-ethicist Andrew Jameton (1988) argued, however, no one has a responsibility to act in ways that he or she cannot perform. Further, while evocation of ‘community’ may be legitimate when referring to those engaged in self-government, it does not capture the realities of the over-regulated lives of the residents no longer entrusted with the responsibility to self-govern. Jameton argued further that even residents who can act responsibly are not obliged to follow the rules of a nursing home into which they were coerced. This also applies to those who entered the home of their own accord, before developing dementia, and were later transferred to the locked unit, where a sense of entrapment and an intense desire to return home is a common response (Vesperi 1987).

### *Community as masked control*

The noisy vocalisations of residents from special-care units suggest individual lament more than a shared sense of community. For some residents, lament signals the realisation of an anticipated loss of control or ability to self-care. But lament is not welcomed in sanitised settings. Institutional settings, which operate through control, demand that one checks such emotions. Cries evince pathology that must be ‘treated’, but their meaning or content is ignored. The inability of a resident to exercise control over her behaviour may lead the staff to try to control it for her, presumably for the good of the entire community. Evoking ‘community’ for such hygienic ends, however, suppresses the very expression upon which community could be realised.

## **Alternative views of community**

In contrast to the usages of community discussed above, the following section presents some alternative conceptualisations that seek to address the problems with the disingenuous applications. The requirement is for formulations of community that take into account both the inter-subjective engagements and the care needs of the residents.

### *Contrasts between communities and institutional settings*

In relational communities, like those described by Dewey (Boydston 1981–90: 334),<sup>3</sup> where common ends are defined and shared, it is reasonable to appeal to communitarian values so that members act for the good of all (Hester 2001). In institutional care settings, however, ‘residents spend most of their time in social isolation’, or at best in ‘pockets of social interaction’ (Hubbard *et al.* 2003: 100). It is unreasonable to appeal to

communitarian values in these settings where alternative values prevail – efficiency, regularity and maintenance – especially when these are irrelevant to those most affected by them. Community theorists have contrasted the values that shape formal institutional settings (like nursing homes) from those of communal or community settings (like one's home) (Hillery 1978; McKnight 1995). Whereas formal settings value efficiency, control, management and contractual justice, communal settings thrive on love, mercy, caring and covenant (Gadow 1988). Controlled and formal settings cannot adequately handle the dilemmas of the human condition, unlike 'true' communities, which embrace fallibility, lamentation and the tragedy of life (McKnight 1995).

*Community as a collectivity or 'we-ness'*

Many conceptualisations of community minimise shared territory or setting and emphasise mutual caring, connectedness and a shared sense among its members of 'we-ness' (Keith 1980; McKnight 1995). Although suggestive of intimate social relations, such 'we-ness' may be a by-product of elaborate organisation (Hazan 1995: 212). Other conceptualisations focus on relationships formed by consent (McKnight 1995), or by collectively-determined goals (Mason 1991) and a sense of 'order and reciprocity' (D'Antonio 1996: 11). Residents of long-term care settings, however, more often regard each other as strangers and lack feelings of mutual responsibility (Jameton 1988). In addition, residents without cognitive impairments often ridicule or direct hostilities to those who are less fortunate (Hubbard *et al.* 2003). The size of the setting may also affect community formation, with considerably more mutual support and caring in small informal facilities than in large institutionalised settings (McAllister and Silverman 1999). There is evidence that cognitively-impaired residents develop relationships, from the simple comfort of silently sitting together (Hubbard *et al.* 2003), to expressions of affection or sexuality (McLean 2001). Even when short-lived, such contact can be intense and the absence of one member can lead to agitation in the other (McLean 1994). But such examples are uncommon. For most cognitively-impaired elders, the effort to develop new relationships by extending beyond their own precarious selves is usually too challenging.

*'True' community versus commodified 'counterfeit' community*

Community theorist John McKnight (1995: x) elucidated the ways in which institutions commodify care and call this a 'service'. He insisted that the commodified substitute can never produce care, because genuine care is the product of the 'consenting commitment of citizens to one

another'; anything less is counterfeit. 'True' communities that cultivate true care are 'uncommodified, unmanaged and uncurricularised' (1995: x and 12). In short, they are not professionalised and neither disciplined nor disciplining (*cf.* Katz 1996). Similarly, medical staff who pursue their activities in a routine and compartmentalised way can never form a community (Hester 2001).

Nursing homes are businesses. Even non-profit homes, especially when large, typically adhere to an efficiency model of time- and task-management, by which both care-givers and care tasks are commodities in the nursing-home market. Commodification introduces objectivity into service delivery, which is destructive of the relationship and commitment of care-givers to the care-receivers as people with needs. Segmented and institutionally-defined care-giving may not resemble the kind of care that the care-givers had anticipated. The different types of demands imposed by efficiency models may explain why devoted care-givers are often penalised for not doing 'real work' (Diamond 1986), or exhaust themselves to satisfy both their own ideals and the institutional expectations. In contrast, efficient task-oriented staff, no matter how insensitive, are regularly rewarded for their work (Foner 1994). Care-giving in the nursing home is curricularised and constrained when the staff members receive regular training sessions about caring for bodies and 'managing' elders. Any innate sense of connection with frail older people must be put aside or disciplined as they become trained in the institution's ways.

### *Community as healing*

As medicalised settings, nursing homes promote cure whenever possible; when that is not possible or lacking, custodial maintenance becomes the goal. These are profoundly different ambitions from the kind of care McKnight advocated. Both cure, which aims for physical recovery, and custodial maintenance, that is concerned with cleanliness and order, are provided through emotional distance. In contrast, care occurs through human connectivity, which helps repair the fragmentation and social rupture that dementia entails. As the locus of cure (a rarity) or custodial maintenance, the nursing home can never provide a substitute for the care and healing that is provided in the community. Contriving to synthesise the two is plainly dishonest (McKnight 1995).

Fragmenting conditions like dementia create both subjective and social ruptures that perpetuate the state of pathology initiated by the condition. For personal healing to occur, the patient must become personally engaged as a meaningful agent in the healing encounter (Hester 2001). Dewey recognised that pathological conditions arise when

the self loses its integrity within the media in which it lives, both somatic and social (Boydston 1981–90: 328–9).<sup>3</sup> In dementia, the self suffers disintegration on both cognitive and inter-personal fronts. Although cognitive reintegration is unlikely, social integration can occur through meaningful re-engagement within a caring community; this is the essence of community healing.

*Community as the foundation of true care*

Care, McKnight insisted, occurs only in informal spaces and through the types of relationships that are available in community settings, not in formal institutions like nursing homes. Care must be given freely without expectations for improvement, lacking any goal but itself (Martin and Post 1992). It depends on the consent, will, and sometimes sacrifice of the care-giver, not the control of or a contract with the service provider (Hillery 1978; McKnight 1995). It comes out of a sense of identity and belonging with the elder. Such idealised care, though rare, does occur. Its motivation derives from the care-giver's spiritual love and communal orientation, neither of which is encouraged or supported by most institutional settings.

Given our inability to reverse or cure most dementias and the penetrating nature of dementing illness on one's sense of self and identity (Estroff 1993), care is where much can be done to sustain failing elders (Carlesen 1999–2000). Not everyone is equipped for care-giving, however, not even in the informal voluntary organisations that McKnight considered 'community'. As Martin and Post (1992: 58) observed, caring is 'a way of being in the world', a source of meaning in life, and a type of faith (*cf.* Goldsmith 1999). Like Gadow (1988), Martin and Post also recognised the immense moral and personal responsibility it imposes on the care-giver to prevent 'the loss of the patient to the disease'. They poignantly added that its only alternative is 'the destruction of the radically infirm' (1992: 57–8).

*Care as spiritual rendering*

Wherever care is lovingly and selflessly offered, whether in an informal community or an institutional setting, the care-giver is motivated by far more than remuneration. In her or his intimate sustenance of another's life and dignity, and dedication to preserve the threads of personhood that remain, the paid or unpaid care-giver is usually motivated by a faith in the divinity of the elder and the dignity this bestows (Martin and Post 1992). I witnessed one devoted care-giver lovingly rendering life and nurturance through inter-subjective engagement with the residents that she served.

Making eye-contact before talking or touching and moving gently to 'test the waters', she proceeded to groom, cleanse and toilet highly-impaired elders. Never pushing, only reaching to support and sometimes amuse, she was an artist in human connectedness, achieving co-operation with the most disturbed people. More often than not, she missed meals lovingly to fulfil required tasks. Her actions were a personal sacrifice to a higher power of which she felt a humble part. Such devotion, she shared, helped to reinforce her own identity and ultimate sense of belonging to something greater.

### *Burnout and the absence of community*

Community in formal settings occurs in such extraordinary relationships. Efficiency-based, instrumentally-oriented formal settings are not designed to support person-preserving ends. Burnout among nursing staff, especially nursing assistants, may be high not only because the work is underpaid or unsatisfying, but because the institution's vision of care contradicts, or falls short of, the care-giver's ideals. Instrumental tasks that are performed in a short, allocated time transform the inter-subjective character of care-giving into practice that objectifies both care-receiver and care-giver. The care-receiver becomes the object upon which procedures and tasks must be performed. The care-giver as commodity can be exchanged for other 'commodities' that produce 'care' and profit. This instrumental vision of institutional care impedes the practice of inter-subjective care-giving that could sustain both giver and receiver (Kitwood 1990, 1995, 1997). In the process, it destroys rather than builds community. This clash of visions and the devaluing of the forms of care-giving that reinforce human connectedness may well provide a more penetrating source of burnout than either poor pay or more general dissatisfaction with the work.

### **Conclusion**

Is community really possible in institutionalised settings like special-care units? John McKnight doubted whether a genuine community supportive of frail elders could occur in settings governed by laws, rules and institutional control. My own and other research has shown that isolated and rare moments of community do occur in such settings, often through the efforts of devoted and devout care-givers. It is necessary to ask under what conditions such community can occur in formal settings. From the observations presented in this paper, the following suggestions are made.

First, relational interaction between care-giver and care-receiver must be prized, and take precedence over instrumental tasks, such as toileting or grooming. Secondly, the fallibility of the residents must be honoured while the care-givers struggle to preserve the strengths of the self (or selves) that remain. Thirdly, in an environment where care and healing are highly valued, efforts to preserve the person should always take precedence over the legal rights that could serve to obviate or diminish him or her (Cole and Holstein 1996). The natural rights of the person would also take priority over the economic rights of the organisation. What is more, the basis for bestowing rights on a person would extend beyond reason (or a rational choice) to include, or even substitute, human qualities such as emotionality, relational capacity, and personal biography (*cf.* Gaylin 1994; McLean 1994). To the extent that these conditions are satisfied, McKnight's informal person-supporting community should thrive, even in unlikely formal settings. But genuine communities are also moral entities, and these are driven by values that oppose the instrumental priorities of institutional entities. For this reason, it is nearly impossible to sustain community in formal institutional settings, even when it appears.

Since extraordinary care-givers can be found in institutional settings, it may seem as if quality care-giving, community and personhood can be achieved if only the right persons are hired and appropriate training is provided. This is however a mistaken view. Care-givers whose standards of care emerge from person-sustaining, spiritual and community values are clearly the exception. They stand out precisely because of their unique motivations as well as the contentedness of those under their care (McLean 2006). The burden for producing true care and true community, however, cannot rest entirely with the care-giver. The obstacles imposed by the institution and by the political economy in which care-giving is commodified and marketed (Estes 1999) are larger impediments to genuine community and care in institutional settings.

The literature that promotes inter-subjective person-centred care, although promising, has had limited impact because it has ignored the radical economic changes that must also occur to actualise such care. Whether such care can be permanently established in institutions is doubtful. Major structural and conceptual transformations in dementia care-giving are needed – from objectified commodity to community. This will require a broad societal revamping of values and priorities. Without such changes, even the most devoted care-givers will eventually burn out and leave. Where instrumental values reign over vulnerable populations under the guise of fostering community, morality is at risk, because managing a community ‘denies the very moral basis upon which the existence

of communal organisations is predicated' (Hillery 1978: 29). In today's technologically-oriented modernity, such is the moral challenge of building true community for both the cognitively-impaired and the rest of us.

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## NOTES

- 1 The term 'special-care unit' was in vogue in the United States during the 1990s (when this study took place) for describing nursing-home units that housed elders with severe dementia. The extent to which special-care units offered specialised care varied immensely. The term has since lost favour, as new models and labels for dementia care have been devised. I retain the term, however, since it reflects the language and model that were current in the study settings.
- 2 Before the observations began, written or verbal consent was obtained from the administrative and clinical staff and legally-responsible family members, and where possible, the residents themselves.
- 3 Cited in Hester 2001.

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