



'Giving and giving back' at the end-of-life: Reciprocal investments between caregivers and residents in the Swiss nursing home context

Original Research

Gabriela Rauber¹, Eva Soom Ammann², Corina Salis Gross³

¹Institute of Social Anthropology, University of Bern; ²Bern University of Applied Sciences, Department of Health Professions, & Institute of Social Anthropology, University of Bern; ³Swiss Research Institute for Public Health and Addiction, & Institute of Social Anthropology, University of Bern

Corresponding author: G. Rauber (gabriela.rauber@anthro.unibe.ch)

ABSTRACT

The present article is based on an ethnographic research project exploring the constitution and reproduction of exchange relationships between residents and caregivers in Swiss nursing homes and elaborates on their significance within end-of-life trajectories. The results show that despite limited personnel, and time and cost constraints in old-age long-term care homes, exchange relationships are significant both in daily interactions and in the context of acute dying. Residents as well as caregivers invest in relationships that build on an informal 'giving and giving back'. Invested goods or services in this exchange are manifold and often immaterial. The main informal investments are: 1) permitting affection and emotional involvement 2) sharing personal information, and 3) offering extra-time. Scant research exists on the reciprocal exchange in care relationships from a theoretical perspective, a gap this study sought to fill. This paper employs anthropological exchange theory to demonstrate how the exchange of these immaterial goods establishes an informal dimension of care that may influence end-of-life practices in the nursing home.

KEYWORDS

Informal relationships, care relationship, end-of-life, 'doing death', dying in institutions, nursing home

FUNDING SOURCE

This work was supported by the Swiss National Science Foundation (NRP 67 "End of Life", see www.nrp67.ch) under grant number 406740_139365/1.

BACKGROUND

1. Informal investments at the threshold of death

The article is based on a research project entitled '*Doing Death and Doing Diversity in Swiss Nursing Homes*', which aims at understanding how nursing homes in Switzerland deal with their increasingly diversified population of residents and staff while striving to provide an individualized dying for every resident (Soom Ammann, Salis Gross, & Rauber, 2017; Soom Amman, Rauber, & Salis Gross 2019). Referring to the perspective of symbolic interactionism on dying in institutions (Sudnow, 1967; Glaser & Strauss, 1968) and more recent studies in this tradition (Salis Gross, 2001;

Dresske, 2005;), the project considers death and dying as the product of interactions between different actors involved. In this sense, staff members, residents and relatives are all co-constructing the dying process together – i.e., they are 'doing death'. In doing so, 'doing death' not only refers to the phase of acute dying, but includes the overall process starting with the resident's admission to the nursing home, which, after a period of weeks, months or years, is followed by a phase of acute dying and is ultimately terminated by the removal from the nursing home post-



mortem. While conflicting notions of an individual 'good death', and issues of diversity in institutional 'doing death' are discussed elsewhere (Ammann et al., 2017; Soom Ammann et al., 2019) the present paper addresses 'doing death' from the perspective of significant informal exchanges within care relationships at the end-of-life.

As a general trend, palliative care policies postulate that patients at their end-of-life should have access to highly individualized care aiming at a self-determined dying in dignity. Organizations such as the World Health Organization state that palliative care must be improved by guaranteeing equal access to every member of society and providing care by well-qualified staff (Connor & Sepulveda Bermedo, 2014). Current conceptualizations of palliative care are no longer limited to patients in specialized units and with malignant diseases, but also includes patients with non-malignant chronic diseases who are cared for in long-term care settings such as nursing homes. However, the aspect that 'good' palliative care is not only achieved by promoting widespread professionalization and accessibility, but also by being attentive to the social dimension of end-of-life care, has not yet received sufficient critical attention. Despite professionals' attempts to take its importance into account in their daily practice, there is a gap in explanations of how professional practice is influenced by the social dimension of care. In particular, there is very little research on informality and informal relationship parts between caregivers and persons being cared for. By exploring concrete investments in care relationships in this paper, we propose a novel theoretical and methodological approach inspired by social anthropology to understand informality in care. In doing so, we hope to inspire end-of-life care discourses and research. Furthermore, as a theoretical lens, anthropological exchange theory may enrich institutional long-term care – a social field of exchange that, to our knowledge, has not yet been studied.

To understand the particular significance of informality in care relationships, the *model of (non-)liquidating transactions* elaborated by social anthropologist Znoj (1995) is used as sensitizing concept. Znoj distinguishes a mode of liquidating transaction between actors who buy and sell quid pro quo goods and/or services in a market-like situation from its counterpart, a *non-liquidating*

transaction. Here, in the absence of monetary exchange, actors engage in a reciprocal circle of investing goods and/or services and thereby build long-lasting informal relationships. Inspired by Znoj's theoretical perspective, this paper discusses the ways and means (investments) by which, informal relationship parts are established, maintained and made sense of at the end-of-life within in institutional long-term care settings. We use the term *relationship parts* to refer to the fact that care relationships are multifaceted, containing formally defined professional and individually established informal parts. Drawing on our own empirical data, we have analysed investments which build the centre of *informal* relationship parts between caregivers and persons being cared for. We will illustrate how this informal 'giving and giving back in turn' may influence the institutional 'doing death' by guiding interactions between caregivers and care receivers in their everyday practice. We will also demonstrate how, in the context of acute dying, caregivers adapt investments and assign particular importance to the informal dimension.

2. Theorizing informality by introducing reciprocity

Anthropology has a long tradition of exploring social and economic dimensions of exchange, paying special attention to the analysis of *reciprocity*, the mutual exchange of goods and services between individuals or groups of individuals. This reciprocal 'giving and giving back' is a focus of classic anthropological theory (Malinowski, 1922; Mauss, 1923; Levi-Strauss, 1969; Sahlins, 1972;) and is considered as a prerequisite of the human need to establish and maintain social relationships. However, anthropological examinations of reciprocity in care relationships within institutions is rare. This is typically explored in the context of other disciplines, such as nursing sciences and feminist economics. Znoj's model of non-liquidation transactions (Znoj 1995), rooted in exchange theory, adds much to this discussion and helps us to describe and understand the construction and reproduction of reciprocity relationships in any setting.

Feminist Economists were among the first to call attention to what motivates people to engage in unpaid care work, suggesting the value of



reciprocity – a mutual ‘giving and giving back’ over time – as a possible motivation for persons to engage in care (Folbre, 1995). Folbre recognized the importance of the ‘nurturing’ aspect of caring, as necessary to maintaining a reciprocal relationship and which, in the absence of payback, can decline. She notices that affection and a sense of responsibility foster reciprocity (Folbre 1995). The significance of affection in informal parts of relationships will be discussed later in this article. While Folbre (1995) recognizes that a time parameter and a continuing investment is necessary to maintain a reciprocal relationship, González-Arnal and Kilkey (2009) point to social embeddedness, and in so doing come close to anthropological or social exchange theory – as a prerequisite for informal relationships. They state that a rational individual makes decisions with reference to the net of social relationships and dependencies (Gonzalez-Amal & Kilkey, 2009). Jochimsen (2003) on the other hand, approaches reciprocity by analysing the nature of transactions, that is to say, by differentiating commodifiable from non-commodifiable parts in care relationships. The instrumental parts of care, such as administering medication, are commodifiable, while the communicative parts of care that make the patient feel cared-for in a social and emotional sense are non-commodifiable. Recognizing that care relationships not only consist of contractual parts with a clear system of payback is a central element to our conception of care relationships and will, therefore, be further investigated with reference to our own data.

Nursing Science is concerned with practices of care, the implementation of care standards and its monitoring, but also with research on caregiver and care receiver relationships. Brown-Wilson et al. (2009) understand reciprocity as a central element of the communal life in nursing homes and categorize factors that condition relationships between all possible actors in the field. The authors identify three types of relationships; pragmatic (focused on the practical aspects of caring); personal and responsive (focused on understanding the resident as an individual) and reciprocal (as a further development of personal relationships, considering every individual’s contributions to creating a sense of community in the nursing home) (Brown-Wilson et al., 2009). Similarly, Adams and Sharp (2013) distinguish between different kinds of care relationships, but,

in contrast to Brown-Wilson et al., (2009), choose a staff-centred approach. They differentiate ‘Positive Reciprocity’ (meaning to be kind to those who are kind to us) from its opposite, ‘Negative Reciprocity’ (referring to the refusal to cooperate, i.e., so-called ‘difficult patients’) from ‘Generalized Reciprocity’ (the expectation that good care given will be paid back to them later by other actors). The latter alludes to a transcending component, the notion that help provided will be returned later by other members of society who accept reciprocity as a social norm. This line of argument is close to classical exchange theory in anthropology and will be further investigated in this article. As a last category, Adams and Sharp develop the term ‘Professional Reciprocity’ and position it close to ‘Positive Reciprocity’ but with a special purpose: It is actively promoted by paid care staff for the purpose of therapeutic benefits for the residents (Adams & Sharp, 2013, p.11). This conception of ‘Professional Reciprocity’ differs from the informal parts in care relationships we are interested in because, according to Adams and Sharp (2013), it is the result of reflection, valorisation and active instigation to benefit from reduced disturbances in the everyday-care-routine. From our perspective, Adams and Sharp’s (2013) ‘Professional Reciprocity’ might be positioned at the threshold of liquidating and non-liquidating transactions. Informal relationships emerge in the context of subjective and situational motivations between individuals who voluntarily start to exchange non-liquidating transactions.

While not specifically focusing on care, *Anthropology* has a long tradition of exploring social and economic dimensions of exchange, paying special attention to the analysis of mutual exchange of goods and services between individuals, families or clans. Ever since Malinowski (1922) visited the Trobriand Islands and described different forms of exchange between family clans (*pure gift* as an altruistic form without expectations for reciprocation and *barter* as self-oriented and profit-minded form, (Malinowski, 1922)), anthropologists have continued to consider reciprocal relationships as a core principle of social structure in communities (Mauss, 1923; Levi-Strauss, 1969; Sahlins, 1972; Gouldner, 1973). In classical theories, which have their roots in colonial anthropology, exchange is regarded as a universal code of relationship building and regulation, most prominently found within kin



groups (e.g., matrimonial exchange, Levi-Strauss, 1969). Exchange relationships are conceived as ongoing circles of transferring goods and services between actors or groups of actors who accept reciprocity as a social norm. This norm obligates them to reciprocate a gift previously received in order to uphold durable social bonds. While classical anthropological exchange theories tend to idealize concepts such as gift exchange and reciprocity as a purely altruistic mode of transaction in small scale communities, more recent theorists refer to models which abandon these idealistic conceptions in favour of a more critical approach, including individuals' economic considerations. Sociologist Pierre Bourdieu, with his distinction of different *capitals* (economic, social, cultural, and symbolic), deconstructed the *gift* as being purely self-oriented and motivated by the individuals' search for accumulating capitals (Bourdieu, 1997). Other theorists, such as Znoj (1995) who further developed anthropological exchange theory, avoided evaluating the motivations behind exchange and focused on describing types of exchange and discerning the associated goods and services.

Little exchange theory research has been done in the context of nursing home care. A few ethnographic studies have been done which consider care relationships by analysing residents' and caregivers' experiences of dying in nursing home and hospice contexts (Salis Gross 2001; Kayser-Jones, 2002; Dresske, 2005;). However, virtually no studies explicitly focus on informal aspects in care relationships in the nursing home or for end-of-life or acute dying situations. As an exception, Ann Russ (2005) presents an ethnographic study of reciprocity relationships between caregivers and AIDS patients in a US hospice. Summarizing how caregivers understand and practice reciprocity at the end-of-life of their patients, she explains:

Because patients were believed able to exert some control over the moment of death, waiting ostensibly until they were prepared and ready, caregivers would 'smooth the way' for patients in the final stages, telling them 'it's okay to let go.' Access to these moments was viewed as a fundamental privilege [...]. [Caregivers] gave the final gift of death. (Russ, 2005, p. 144-145)

Arguing that caregivers interpret their participation in someone's death as a 'gift', is not a thesis we can confirm from our own set of data and must be considered within the special context of hospice ideals and discourses. Nevertheless, Russ (2005) attentively describes how caregivers interpret reciprocity relationships with their patients. The privilege of sharing somebody's death (the 'gift') is thought of as being compensated by first enabling the patient a 'good death' and then by preserving the deceased's memory or by mourning his/her death. Describing the goods or services transferred, she gives a vivid example here of what non-liquidating 'giving and giving back' in care relationships can look like.

Znoj's (1995) model of transacting goods and services distinguishes two modes of transactions: the *liquidating* and the *non-liquidating* mode. The first mode refers to two (or more) actors who approach each other in a short-term relationship to exchange a good or service (e.g. seller and client in a store). The service or good provided is settled by a clearly defined payment, so that the partners are free of any further obligation to reciprocate or 'give something back' in the future and will not engage in a social relationship either. Liquidating transactions typically structure market-guided societies with their manifold possibilities to purchase or offer items either virtually or in face-to-face interactions. Znoj's (1995) understanding of liquidating transactions can be further enhanced through Gregory's description of *commodity*, which states that '[c]ommodity exchange is an exchange of alienable objects between people [in] a state of reciprocal independence.' (Gregory, 1982, p. 41). For Znoj (1995), alienability is central to distinguishing the two modes of transactions.

The second mode, non-liquidating transactions, focuses on reciprocity, which in Znoj's definition is the product of exchange practices between social actors (1995, p. 124). Non-liquidating transactions also involve two or more partners who exchange goods or services. Here, however, transactions are based on an informal 'giving and giving back in turn', which means that a good or service received is not returned immediately, nor is the form of reciprocation clearly defined. Instead, the transaction leaves a debt to reciprocate later in a vaguely outlined manner. In Znoj's terms, the non-liquidating transactions produce a 'net of mutual obligation' (Znoj, 1995, p. 124). As a



consequence, transactional partners establish and reproduce a social relationship between inalienable partners (Znoj, 1995, p. 125), which centres on repeatedly exchanging goods and counter-goods (e.g., informal work loan between neighbouring peasants). The degree of social integration is therefore a distinctive characteristic. While liquidating transactions do not ask for a community in which exchange should take place, non-liquidating transactions and the perpetuated informal exchange of services and goods clearly lead to a social integration of the actors who establish and reproduce community (Znoj, 1995, p. 124-125).

From the very beginning, anthropologists have consistently shown a considerable interest not only in transactional partners and informal exchange practices, but also in the concrete goods and services transferred (e.g., the traditional 'Kula Ring' on the Trobriand Islands and its cyclic exchange of necklaces, Malinowski, 1922). In peasant societies, exchange often consisted of agricultural goods, tools to process these goods or assistance in the form of loaned workforce (see Znoj 1995). When considering the context of institutional care relationships and the fact that informal relationship parts also exist, what goods and services might be exchanged becomes central.

Several authors have mentioned such goods in their studies. However, often with a prior interest in the asymmetries within care relationships which is especially relevant when discussing the quality of care. Transactional goods are mentioned as an example rather than an analytical concept or category. Noteworthy is the most recent contribution to the subject by Molterer et al. (2019). Referring to Mol (2008) they discern two different logics of care (professional and relational) and argue that 'care is always a matter of tinkering with different, sometimes competing 'goods'' (Molterer et al., 2019, p. 95) which in practice lead to a 'practical ethics of care' (Molterer et al., 2019, p. 95). For our perspective, these examples are significant because they give a first impression of the ways and means by which actors engage in informal relationship parts in the care context.

Interestingly, when 'goods' are described in literature they often show similar characteristics. First, most investments described are *immaterial* instead of physical products, and second, they

show that contributions made by the caregiver and those made by the care receiver may be of different form. While for caregivers, emotional involvement such as the desire to help frail persons (Waerness, 1987) or strong feelings of attachment (Himmelweit, 1999), compassion (Meagher, 2006), or the deliberate investment of extra-time (Davies, 2001) is meaningful. Contributions by the care receivers include cooperation with the caregiver's requests (Meagher, 2006), taking over little chores in order to disburden the caregiver (Bowers, Fibich, & Jacobson, 2001) and sharing aspects of their past lives (Bowers et al., 2001). As we can see from these examples from the studies above, caregivers and care receivers 'give' and 'give back' varying immaterial favours and, thereby, invest in a personal relationship.

Our paper aims at further developing these observations. By using Znoj's (1995) model and our own extended set of data, we explore the establishment and maintenance of everyday interactions in the nursing home context as fundamental elements of informality in care relationships. Furthermore, focusing on dying trajectories, we also discuss the termination of informal care relationships. Doing so, we aim at improving the understanding of the significance of informality in care relationships; the 'giving' and 'giving back' at the end of life.

METHODS

3. Exploring informality

An open ethnographic study design following the classical, theory-generating principles of Grounded Theory (Glaser & Strauss 1967, 1968; Small & Gott, 2012;) was chosen to understand the particular relationships involved in practices of 'doing death'. Two Swiss nursing homes were selected for a fieldwork phase with nine months of participant observation; the *Center Burgallee* and the *Brunnhof*. Both nursing homes are located in urban, German speaking areas of Switzerland and accommodate up to 130 elderly residents. Data collection included taking extended field notes to document observed informal interactions on a daily basis. In addition, open and semi-structured interviews were conducted with staff, residents, family members, and experts from outside the institution. The interviews were selectively audiotaped (if circumstances allowed for it) and



transcribed. Data gathering and data analysis was conducted iteratively and assisted by Atlas.ti software. All data was gathered and edited in German. For the purpose of this article, selected sections were translated into English. In a process of constant comparison, data was contrasted and triangulated continuously both within the research team and outside (external experts/researchers). During their field stay, the researchers regularly participated in inter- and supervision meetings to reflect on their own position as a researcher. The study followed the ethical standards defined by the Swiss Ethnological Society. Access to the nursing homes and approval of the study was granted by the nursing home managements. Informed consent was obtained iteratively (process). Prior to field entry, all participants were informed of the aim of the research by the management. During the field stay, participant consent to participate was re-affirmed by the researchers.

To minimize disturbances caused by the research project, it was decided that only one researcher should be introduced per institution and that the nursing home management should select the ward for them. The first author was assigned to the Center Burgallee, which she entered by introducing herself as a member of the research team and by explaining that she would start doing research by working several weeks as a caring aid. After this first phase, the researcher started moving around more freely on the ward. Striving for a previously planned change of perspective from caregiver to care receiver (which was made visible by no longer wearing the blue nursing gown), she started accompanying residents throughout their day, taking them out for a walk and conducting informal talks, also with residents whose radius was limited to their room or bed. In her field notes she describes her experiences associated with this role shift:

For a week now, I have been spending whole days with particular residents. There was some confusion at the beginning (both Mrs. Huber and Mr. Ramo didn't recognize me in my own clothing) but after making clear once more who I am, the residents willingly spent their time with me, as they stated. Mrs. Sager said that nurses are always in such a hurry and hardly come by in the afternoon. Especially the hours between 'midday rest' and dinner, which residents describe as, 'long', 'bland' or 'boring'. During the afternoon,

there are only few staff members working (most work the morning shift and come back for dinner) and if neither therapy nor visits offer distraction, residents tend to be left to their own devices in the afternoon hours. (G. Rauber)

While more staff members are present in the morning shift when medical treatments and bodily care are generally executed, the afternoon shift is called 'Hüeti'. The term can best be translated as the 'herding shift' and it implies that few caregivers have to 'herd' or to look after many residents. When thinking about informal relationships, these circumstances are noteworthy: The afternoon, being the time *after* morning routine and lunch time but *before* evening routine and dinner, would offer an occasion to invest in informality and personal relationships between caregiver and care receiver. However, most staff members are not present during the afternoon, and the few who are, are busy to meet with residents in need of more intensive care. It is thus the task of relatives or volunteers to spend the bland afternoon hours with residents. For the researcher, these circumstances offered an opportunity to explore informality by establishing individual relationships with residents and to talk about issues that needed more time and privacy. At the same time, sitting for hours at a bedside, the researcher experienced herself how long afternoon hours may become if possibilities for activities are limited.

During the next phase of fieldwork, the actor-centred perspective was abandoned in favour of a case-centred one, shifting the focus of attention to concrete dying trajectories. Whenever possible, the researcher then spent time in a dying resident's room and with institutional actors responsible for dying persons. The fact that personal relationships with residents had been built previously proved to be an advantage in many cases, permitting the researcher to be present in this intimate situation without being 'out of place' with respect to the staff, the residents, and their family members. In total, eighteen dying trajectories could be observed. Involvement ranged from little participation (e.g. visiting a dead body in the nursing home's mortuary and conducting post-mortem interviews with staff or family members), to intensive participant observation during the acute dying phase and after death (spending hours or days at the bedside of a dying resident, participating in special team meetings, observing



and talking about care routine for the dying resident, assisting with the so called 'comfort care' which aimed at reducing pain, anxiety and unnecessary medical treatments, helping staff to prepare the dead body and taking part in the funeral).

4. Dealing with ambiguity and informality

Observing everyday interactions allowed the researcher to address the question in detail of how informality emerges within care relationships in the nursing home. At a first glance, the relationships between caregivers and care receivers are primarily structured by the nursing home organization, which is based on a clearly defined, *formal* system of contract and monetary account. As part of this organization, the degree of care and support an individual resident is in need of (nursing care level) is regularly evaluated, and care services are then provided by caregivers and paid for by the residents, their health insurance and the state (supplementary benefits). In accordance with this structure, there are institutional rules for professionals on how to address residents properly (e.g., addressing them formally by using family names instead of first names or holding a resident's hand instead of caressing his/her cheek, (Soom Ammann et. al, 2019)) which are considered by professionals an appropriate balance of closeness and distance within the care relationship. However, after several weeks of experiencing and reflecting on the nursing home, the ambiguous nature of care relationships became more and more visible to the researcher. It became apparent that some residents and institutional caregivers selectively engage in *informal* relationships with each other. This first became obvious in everyday conversations: staff members, when among themselves, would often talk about their problems with some residents and their sympathy for others. Similarly, residents, when alone with the researcher or when talking to each other, articulated their affection for or aversion towards certain staff members. It seemed that every person on the ward disposed of a certain knowledge on the nature of most care relationships. In this sense, everyone knew that Mrs. Huber liked Nurse Samantha and complimented her. Then, after some more time in the field, this ambiguity also became observable in other forms of everyday interactions on the ward. For example, when adapting shift plans, staff members applied ad hoc strategies to

omit or diffuse conflicting situations (e.g., by not assigning staff members to residents whom they did not get on with very well). So, the staff knew that nurse Elisabeth had to be sent to Mrs. Santini if the resident with severe depression refused to get up in the morning. Also, residents contributed to the ambiguous character of care relationships, for example when waiting to communicate a particular information or problem until a nurse was in charge with whom they felt familiar. To sum up, both groups of actors point to informality in care relationships. However, this occurred rather implicitly in everyday interactions without reflecting the fact that care relationships have an ambiguous character and without thinking of its significances for the institutional 'doing death'.

Observing dying trajectories more closely in the later stages of field research allowed the researcher to address informality under the circumstances of imminent dying. It became evident that, for caregivers, 'doing death' with 'their' residents led them to negotiate and rethink the pervasive time and financial pressures. In this sense, it could be observed that nurses voluntarily spent extra hours at the end of their shift if they wanted to stay with a resident with whom informal relationship parts had been built previously. It could therefore be argued that at the moment of being confronted with acute dying, the ambiguous character of care relationships intensified and became better observable. We will now demonstrate in detail how pre-existing informal relationship parts between staff members and dying residents lead to an increased investment of non-liquidating transactions. By analysing the goods and services that are invested, we will demonstrate the significance of informal relationship parts in the context of 'doing death'. Moreover, we will try to explain why such relationships are established in the context of the imminent threat of rupture caused by death. Eventually we will see that permitting ambiguity in care relationships is an effective strategy for dealing with the rupture and making sense of it. It is thus a constitutional element of 'doing death' in the nursing home.

5. Handling rupture

There are remarkable differences between informal aspects in institutional care relationships and other, more traditional exchange relationships described in anthropology. Kin groups or peasant



communities are socially and economically rooted in the mutual 'giving and giving back in turn'. Informal exchange is essential for their existence. The loan of workforce or the exchange of material goods is used over generations to profit from a stable net of social relationships. In care relationships, the motivation to build informal bonds is less evident. Care is primarily provided in a liquidating mode to a customer (resident) who pays for the service. With the resident/customer's, death the service ends. Thus, from this perspective, a care relationship is not supposed to influence end-of-life practices substantially because actors are thought of as being alienable. Also, in institutional care, relationships do not persist over generations. Relatives of a deceased resident are unlikely to engage in a future relationship with the former caregivers of their father, mother, etc. (at least the authors have never made such observations). However, with informal relationship parts, a resident's death requires caregivers to handle this rupture, cope with feelings such as loss and grief, and move on to build new care relationships with future residents. So, why do caregivers engage in informal relationship parts in a context where death is always certain, leaving them to cope with a ruptured exchange dynamic? Nurse Seraina, interviewed following the death of a resident, reflects on her motivations to engage in informal relationship parts while 'doing death':

They have done their part for the family or even for the society, if you want – they have raised children, worked and paid taxes. I am the one to give them something back at the end, be there for them when their time has come to say goodbye. This is nothing but right. It's part of what I think is meaningful in my job. (Seraina, nursing aid at Center Bургallee)

Nurse Seraina refers to a moral obligation to 'give something back' to members of the elder generation, and she also mentions a satisfaction associated with fulfilling this obligation. We could argue that 'giving back' in her view is not only a subjective emotional satisfaction but has the ability to transcend in a manner comparable to the context of small scale communities: a member of the previous generation has invested goods/services in favour of the community. Seeing herself as a member of the next generation, who is morally obliged to return investments, she is ready to intensify informal relationship parts in the

context of dying. This transcending notion of 'giving and giving back' is not necessarily rooted in altruistic motivations but refers to a notion of persisting intergenerational exchange over time, which will include her own end-of-life. This would mean that her investments are accompanied by a hope that other people will feel a similar urge to contribute to her own end-of-life care.

We will now give deeper insight into empirical data and discuss three main categories of non-liquidating goods: *Permitting Affection and Emotional Involvement*, *Sharing Personal Information and Offering Extra Time*. As stated before, some of these goods have already been mentioned by other authors. However, their categorization and valorisation as integral parts of 'doing death' is new and is thus intended to add to the existing literature.

RESULTS

Permitting affection and emotional involvement

The researcher collected a large amount of data that points to close emotional involvement in care relationships. Small signs of affection sometimes get lost in day-to-day practice, however, interactions during acute dying phases and post-mortem interviews with staff members clearly bring to light the ways residents and staff members establish an informal relationship, as illustrated in Mrs. Huber's case. Suffering from an early-onset Alzheimer dementia that progressed quickly, the resident roamed the corridors in her wheelchair, day after day, and constantly in search of a 'person in white clothes' who would hold her hand, take a chocolate she offered and drink an espresso with her. Although challenging the daily routine on the ward (i.e. Mrs. Huber was a 'time consuming resident'), her need for constant presence of staff members was met by keeping her nearby whenever possible. Half a year later, Mrs. Huber retreated from the public space of the nursing home (corridors, dining room, TV corner) to the private sphere of her room, and shortly afterwards to her bed. Losing physical strength and her intense need for company, she stayed in her bed without eating or speaking and died two weeks later. Reflecting on the period of retreat before her death, nurse Anna and nursing aid Sina state:



Anna: We always took her with us. If she saw there was a person in a white nursing gown, she felt safe and relaxed. Like that it happened all the time; she had a strong presence in our daily life.

Sina: When she was about to go [die], we suddenly did not have her with us anymore, did not get her daily hugs and caresses anymore. I really have to say, I felt a strong wish to go to her bed and hold her hand.

When asked, whether she had the time to go to sit at her bedside, Sina replied:

Well, I just made the time to go there because I felt a strong wish to do so.

The researcher tried to spend time at Mrs. Huber's side during her last two weeks of life. Doing so, revealed to her that many staff members tried to make frequent contact with the dying woman. They would enter her room noiselessly, hold her hand or say a few words with a soft voice, and at times shed some tears. Having spent already several months in the field by that time, the researcher recognized the exceptionality of this particular 'doing death'. The fact that so many staff members showed such an intensive emotional and time-consuming involvement in a dying trajectory was outstanding to all wards in the Center Burgallee. The case even became more remarkable because usually, especially if extra time consumption coincided with openly shown discontent on the 'difficult' resident's side, the retreat to bed and loss of verbal communication tended to be perceived as 'disburdening' to the daily routine, and time shared at their bed side was reduced to the well-defined liquidating care services (e.g. repositioning, refreshing face and mouth, administering medication, making reports to the doctor).

Meeting nurse Anna at lunch some days after Mrs. Huber's death, the researcher asked her how she had experienced the resident's dying in comparison to other dying trajectories and the nurse replied:

Well, the wish to be there depends on the situation. She [Mrs. Huber] always gave such a lot of herself. She suffered from dementia, but she could hug you and say 'I don't know where I am but I know you are kind.' That touches your

heart. It really hurt when she left, even if I was glad for her that she could go.

What becomes clear here is that it is impossible to consider the moment of retreat and the process of dying without looking back at the earlier day-to-day interactions. By repeatedly expressing her affection for the caregivers and by articulating her need for constant physical and emotional closeness, Mrs. Huber, although severely impaired, would invest considerable non-liquidating goods that invited caregivers to reciprocate. This becomes obvious when considering that the caregiver explains her wish to be with the dying Mrs. Huber by referring to the reciprocal character of their relationship ('she gave such a lot from herself'). Interestingly, efforts to invest into the relationship with the resident were shown not only by a single nurse, but by the majority of staff members on the ward. It might be argued that, over time, Mrs. Huber has transcended her non-liquidating investments (affection, compliments, caresses, and gratefulness for companionship) from single caregivers to all actors dressed in white nurses' clothes, what could explain why visits at her bedside have been so exceptionally frequent in general. The informal relationship seems to have spread to all possible care relationships on the ward, evoking an emotional involvement that expressed itself in a strong wish to participate actively in her 'doing death'. It can be argued that the strong emotional involvement of most staff members led to temporarily re-structuring the daily routine on the ward, permitting that a particular 'doing death' absorbs working time which would otherwise be occupied by care tasks for other residents.

Twenty-four hours before her death, Mrs. Huber was considered by staff members as 'about to go'. Signs that were explained to the researcher as being reliable indicators that death was imminent (jarring breathing, macerated skin, missing response to any kind of intervention) led the caregivers to adapt their practices of 'doing death' once more which included investing their off-work time. Several nurses would stay on the ward after the end of their shift. Two nurses even dropped by during their recreation time, with no other reason to come but ask how Mrs. Huber was and enter the resident's room for a short visit. They were well aware that the resident was no longer able to actively 'give something back' from her



side, but, facing the coming rupture of the relationship, they strove to 'give' as much as possible. What they 'got back' for their accumulated investments should again be considered from a transcending perspective, as Anna's words suggest. She is grateful that the person she felt strongly attached to 'is able to go now', which in her view signifies a relief from suffering. Feeling reassured that everything has been done the 'right way' (which is subject to the caregiver's personal interpretation) can be understood as a 'gift back' that leads to satisfaction and comfort. Both are important not only to cope with the present rupture and loss, but also for the motivation to engage in future informal relationships with residents.

Sharing personal information

The researcher quickly learned that some residents shared information about their private lives with some caregivers, but not with others. For example, during the morning routine (a period of high activity on every ward, see also Costello 2001), residents in relatively good health used the opportunity to chat vividly about their lives, while getting support in washing, grooming or being taken to breakfast. Undergoing the same morning routine accompanied by another staff member, the same resident seemed to be rather ill-humoured or silent. As the researcher discovered bit by bit, the criteria by which personal information was shared with a caregiver was the construction of similar identities or experiences which led to personal appreciation and trust.

Spending an afternoon with Mrs. Rudolf, a 99-year-old woman, the researcher had a conversation with her about her relationships with staff members. She loved to talk about her childhood memories to Nadja, a middle-aged nursing aid, she said. She could tell her about the cuckoo clock, a matter nobody else was interested in. Born in Germany, she had childhood memories of it, she said. During World War II's air raids, the grandmother would cradle her on her lap, rocking her gently in time with the clock's tick tock. They had no basement to hide in and she was scared, she said. But she would never forget the feeling of comfort on her grandmother's lap. Nadja was the only one she could share that story with. "The young girls would laugh at me and the others don't care."

Occasions as described by Mrs. Rudolf are very frequent. Residents demonstrate their willingness to give additional personal information to a certain staff member and thus open the opportunity to engage in an informal relationship. Staff members react by keeping the conversations concentrated on the residents' matters that are relevant for providing adequate care. Or, as Nadja did, they can respond by showing interest in the story and by taking up the thread and give some personal information themselves. Exchanging personal information between staff members and residents can be a powerful means to establish informal relationships because it can be considered as an attempt to transcend positions in the asymmetry of a care relationship. It could be argued that the resident steps aside from his/her role as a frail care receiver. Similarly, the staff member abandons his/her role as a professional caregiver. Both then become transactional partners who equally engage in an informal relationship based on the exchange which then co-exists with the formal care relationship.

When interviewed by the researcher about her relationship with Mrs. Rudolf, Nadja started talking about the clock herself. She had an important memory associated with a German clock on her own, she explained. "That's our story", Nadja stated to the researcher. "No one knows. It is almost like a little secret [...] sometimes it's the little things that make the difference."

Four and a half months later, Mrs. Rudolf entered the acute dying phase. Nadja was eager to be put in charge of Mrs. Rudolf. One morning, after having 'refreshed' the resident, the nurse sat down on the edge of the bed and put her arms around the petite woman. Then she started humming and cradling her very gently to the tick tock of the clock in the otherwise very silent room. Becoming aware of the intimate character of the scene, the researcher left the room. Mrs. Rudolf died the next day and Nadja prepared the body for the mortician.

During the whole fieldwork, the researcher had never seen a staff member sitting on a resident's bed, and it is likely that some other team colleagues would have termed Nadja's behaviour as 'unprofessional'. As observed, staff members usually sit or stand at the bedside when they hold



the hand of a dying resident. The bed is the most private realm of a care receiver in the semi-private sphere of the nursing home. Sitting on it and embracing a dying resident might be considered as an act of transgressing the border of intimacy. Mrs. Rudolf could not be asked whether she felt comfortable with this intimate physical contact. However, blurring the boundaries of privacy here should be seen in the context of a well-established informal relationship and the staff member's attempt to give comfort in a possibly fearful situation (dying) as her contribution to a personalized 'good death'. The two individuals have shared intimate private information, and, while referring to common experiences, built a base of mutual confidence. Sharing personal information or 'secrets' can thus be seen as strongly influencing practices of 'doing death' well in Mrs. Rudolf's case. 'Doing death' without referring to the clock story would not have been a 'good death' in Nadja's view. Therefore, a 'good death' (whatever it is considered to contain in the subjective case) can be enhanced by non-liquidating transactions in informal relationship parts between caregiver and care receiver.

Offering extra time

Having entered the field as a nursing aid herself, the first author quickly learned that caregivers constantly need to manage time and cost pressure in their everyday routine. Especially when staff members on sick leave were not replaced or when a considerable number of residents were in bad health condition, the workload was heavy. Several times, the researcher experienced on her own how difficult it was to spend an adequate amount of time with a resident when six more were waiting for help. It was not surprising then that many staff members reported in interviews that often only 'basic' care services could be provided, meaning the help to get up, to get washed and dressed and to eat, as well as administering the medications. While these daily care services were always provided without exception, time for the social relationship was scarce (e.g. chat with a resident about everyday concerns). It seemed that residents were left in a position of having to ignore their social and/or emotional needs (at least when no family or friend was available) and be content with what they received in the hectic nursing home routine. However, particularly in the context of acute dying, time pressures became negotiable

depending on the informal relationship parts involved. The following case of Mrs. Adani illustrates how time resources may be mobilized when strong informal parts in the care relationship are at stake while 'doing death'. Time is, therefore, an important transactional good used to prepare to and cope with the coming rupture caused by a resident's death.

Mrs. Adani, 71, entered the nursing home after a cerebral tumour had rendered her incapable of walking and attending to her personal hygiene. Ramesha, as she preferred to be called by her first name, was of Tamil origin and had migrated to Switzerland together with her husband during the civil war in Sri Lanka. On ward Beta, she was known as a charming, grateful and humble person who never made demands. Ramesha's daily care proved to be little complicated, and the researcher was willing to help her with her morning routine whenever help was asked for (which happened several times a week). Doing so, the researcher discovered that apart from her, two staff members also spent a considerable amount of time with the resident including Devika, a registered nurse with Indian origins, and Soorat, a nursing aid, born in Sri Lanka. Both staff members would often spend their break time with the resident or drink a tea with her after the end of their shift. It was part of the daily nursing routine that one of the two staff members helped her with her morning routine (when the researcher wasn't entrusted with this task). It was a special gift to have them on the ward, Ramesha said, it was such a pleasure to chat with them in her mother tongue. Soorat, who lived close to the nursing home, would sometimes even come to visit her on Sundays, the resident added.

Ramesha died rather unexpectedly. All of a sudden, she suffered from heavy pain and breathing difficulties. She was given high doses of opiates; nevertheless, her pain was difficult to control. The day she died, Soorat was working the early shift. It was painful for her to see the resident in such a terrible condition, she said. Devika had her day off but suddenly appeared on the ward in civil clothes, tears in her eyes. Soorat had called her in, she explained to the researcher. When Ramesha died, her husband requested that his wife be dressed in her wedding sari. Long after her shift had ended, Soorat was willing to prepare the dead body together with Devika. Charlotte, who was working on the day, later told the researcher that



she was glad that the two colleagues helped to dress Ramesha in the sari. “They are the only ones who know how to wrap somebody in ten meters of silk”. One week later, the researcher participated in the funeral ceremony. She was accompanied by Devika and Soorat, both openly grieving. In an interview they later stated that they both had deliberately ‘sacrificed’ their day off to come to the funeral without calculating it as work time. A gesture that in Devika’s words was ‘natural’ to give a last farewell and also to find comfort herself.

As has been evidenced, actors engage in informal relationship parts at various levels of intensity while dealing with the threat of rupture. However, the investments described such as extra time or affection are not rigid. They are subject to negotiation and interpretation depending on the varying circumstances and meanings ascribed by actors. This becomes most evident when considering many caregivers’ efforts to intensify investments during the last days and hours of a resident’s life.

6. No second chance or ‘doing everything right’

To understand the practices of intensifying investments when death becomes foreseeable within days or hours, we need to consider death from a different perspective - as a unique event in every (human) beings’ existence, and caregivers’ ambition to ‘do everything right’ must be seen with regard to this uniqueness. Staff members who have maintained strong informal relationship parts with a resident are well aware that there will be no second chance to ‘make it better’. Therefore, they lay special importance on ‘making everything right’ to enable the resident a ‘good death’, whatever ‘right’ and ‘good’ may include for the actors involved.

Already within the first two weeks of fieldwork, the researcher was confronted with a dying trajectory that illustrated the significance of ‘doing everything right’ while ‘doing death’. The registered nurse Ashanti approached her; visibly irritated, stating that Mrs. Albert had just died. Having seen the resident just one hour before, the researcher shared her astonishment. She just seemed a little tired, Ashanti said, and she wanted to rest. Ten minutes later, the nurse found her lifeless on her bed. Ashanti was deeply moved, she said. The woman had died alone and very quickly.

Nobody had anticipated that she would die so soon, as she explained.

By that time, the researcher did not fully understand why the nurse was so irritated about the resident’s sudden death. Mrs. Albert was 89 years old, and she died without having to lie in bed for days; aspects that staff members often tend to interpret as elements of a ‘good death’ (i.e. without pain or being confined to bed for a long period). Weeks later, however, Ashanti’s agitation became more comprehensible to the researcher while talking to Charlotte. Mrs. Albert’s death occurred unprepared, leaving the nurse no opportunity for actively ‘doing death the right way’, or as Charlotte puts it:

There is no second chance to make it better. So, you try to do everything as good as you can. I don’t care about working hours in that moment. Instead, I hope that they can go within the next hours so that I can stay with them until the last breath [...] and say a last goodbye.

Charlotte explains what ‘doing everything right’ can mean. She expresses a strong wish to accompany the resident until the ‘very end’ of the dying trajectory, and the fact that she is possibly working extra hours to achieve that goal doesn’t matter to her. However, we would argue that quite the contrary is the case: Deliberately dedicating extra time or work here is indeed an essential part of ‘doing everything right’ while ‘doing death’ and this is what Ashanti missed when confronted with the death of Mrs. Albert. The sudden death did not give her the chance to prepare and make sense of the coming end of the relationship. The opportunity to make sense of rupture is integral to caregivers’ present and future involvement in informal relationship parts with other residents.

DISCUSSION AND CONCLUSION

7. Making sense of the threat of rupture

Using Znoj’s (1995) exchange theoretical model of (non)-liquidating transactions as a sensitizing concept we have shown an innovative way to understand the particular significance of informality in care relationships in the nursing home. We have used selected ‘investments’ to understand the ways and means by which informal relationship parts are established, maintained and



made sense of in the context of everyday practice and we have drawn attention to acute dying trajectories to demonstrate how caregivers tend to assign particular importance to the informal dimension when the threat of rupture by death is imminent.

As demonstrated, if the circumstances of a dying trajectory do not permit enough time and space to adjust investments so that they enable what the caregivers in question consider to be a 'good death' it is likely that they will feel more challenged to accept a resident's death and think back on it remorsefully. What is missing in this situation is not only the informal investment of 'time' for a dying resident, but in the broader context it is the opportunity to make sense of the ever-present threat of rupture in the nursing home. That is to say, caregivers who engage in informal relationship parts – and in our research these were the majority of staff members observed – are challenged to 'do death' in a way that they can make sense of within the cycle of establishing, maintaining and terminating relationships. Making sense of rupture is then part of the process of actively preparing to let go by intensifying investments of reciprocity. Shared memories with the resident and reflections on what made their relationship personally meaningful thereby often serve as a reference to decide in what particular way to adapt investments (e.g., increasing presence during shift or making extra appearances at night). Caregivers who go through this process often express that they are 'relieved' or 'grateful' after a resident's death and that they find comfort knowing that everything was 'done right' for the person. They may also be more likely to be deliberately involved in future informal care relationships than caregivers who experience repeated unprepared ruptures. However, with reference to our data, we argue that the majority of caregivers repeatedly engage to some extent in informal relationships with residents, despite the awareness that they will have to cope with loss again. In practice, trying to omit close personal bonds to protect oneself from grief doesn't seem to be a widely used strategy. From an anthropological perspective this is less surprising than it might appear. Establishing and maintaining social relationships is a basic human need and making sense of it is a constant in human activity. This is not only true for close social bonds with family and friends, but also for relationships which are framed

by a formally defined institutional structure such as the nursing home.

While nursing homes cannot structurally implement and control informal relationship parts, institutions can valorise them as an essential part of daily care practice which influences end-of-life situations and practices. Drawing a detailed picture of informal parts in caregiver/care receiver relationships in nursing homes is important, adding new insights into the ways institutional long-term care relationships are structured and interpreted by the individuals involved.

REFERENCES

- Adams, V., & Sharp, R. (2013). Reciprocity in Caring Labor: Nurses' Work in Residential Aged Care in Australia. *Feminist Economics*, 19(2), 100-121. doi:10.1080/13545701.2013.767982
- Bourdieu, M. P. (1997). Some additional notes on the gift. In *The logic of the gift: Toward an ethic of generosity* (pp. 131-141). New York: Routledge.
- Bowers, B. J., Fibich, B., & Jacobson, N. (2001). Care-as-Service, Care-as-Relating, Care-as-Comfort. *The Gerontologist*, 41(4), 539-545. doi:10.1093/geront/41.4.539.
- Brown-Wilson, C. R., Davies, S., & Nolan, M. (2009). Developing personal relationships in care homes: Realising the contributions of staff, residents and family members. *Ageing and Society*, 29(7), 1041-1063. doi:10.1017/s0144686x0900840x.
- Connor, S. R., & Sepulveda Bermedo, M. C. (2014). *Global atlas of palliative care at the end of life*. London: Worldwide Palliative Care Alliance.
- Costello, J. (2001). Nursing older dying patients: Findings from an ethnographic study of death and dying in elderly care wards. *Journal of Advanced Nursing*, 35(1), 59-68. doi:10.1046/j.1365-2648.2001.01822.x
- Davies, S. (2001). *Wanting what's best for them: Relatives experiences of nursing home entry: A constructivist inquiry* (Doctoral dissertation, University of Sheffield). Sheffield: School of Nursing and Midwifery.



- Dresske, S. (2005). *Sterben im Hospiz: Der Alltag in einer alternativen Pflegeeinrichtung*. Frankfurt A.M: Campus.
- Folbre, N. (1995). "Holding hands at midnight": The paradox of caring labor. *Feminist Economics*,1(1), 73-92. doi:10.1080/714042215.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Glaser, B. G., & Strauss, A. L. (1968). *Time for dying*. London: Routledge.
- González-Arnal, S., & Kilkey, M. (2009). Contextualizing rationality: Mature student carers and higher education in England. *Feminist Economics*,15(1), 85-111. doi:10.1080/13545700802528323.
- Gouldner, A.W. (1973) *For sociology: Renewal and critique in sociology today*. London: Allen Lane.
- Gregory, C.A. (1982). *Gifts and commodities*. London: Hau.
- Himmelweit, S. (1999). Caring Labor. *The Annals of the American Academy of Political and Social Science*, 561, 27-38. Retrieved February 15, 2021, from <http://www.jstor.org/stable/1049279>
- Jochimsen, M. A. (2003). Integrating vulnerability: On the impact of caring on economic theorizing. In *Towards a feminist philosophy of economics* (pp. 231-246). London: Routledge.
- Kayser-Jones, J. (2002). The experience of dying: an ethnographic nursing home study. *The Gerontologist*,42(3), 11-19. https://doi.org/10.1093/geront/42.suppl_3.11
- Lévi-Strauss, C. (1969). *The elementary structure of kinship*. 2nd ed. Boston: Beacon Press.
- Malinowski, B. (1922). *Argonauts of the Western Pacific: An account of native enterprise and adventure in the archipelagos of Melanesian New Guinea*. London: Routledge and Kegan Paul.
- Mauss, M. (1923). *Essai sur le don forme et raison de l'échange dans les sociétés archaïques*. *L'Année Sociologique* (1896/1897-1924/1925), 1, 30-186. Retrieved February 15, 2021, from <http://www.jstor.org/stable/27883721>
- Meagher, G. (2006). What Can We Expect from Paid Carers? *Politics & Society*,34(1), 33-54. doi:10.1177/0032329205284755.
- Mol, A. (2008) *The logic of care: Health and the problem of patient choice*. New York: Routledge.
- Molterer, K., Hoyer, P., & Steyaert, C. (2019). A Practical Ethics of Care: Tinkering with Different 'Goods' in Residential Nursing Homes. *Journal of Business Ethics*,165(1), 95-111. doi:10.1007/s10551-018-04099-z
- Russ, A. J. (2005). Loves Labor Paid for: Gift and Commodity at the Threshold of Death. *Cultural Anthropology*, 20(1), 128-155. doi:10.1525/can.2005.20.1.128.
- Sahlins, M. (1972). *Stone age economics*. Chicago: Aldine.
- Salis Gross, C. (2001). *Der ansteckende Tod: Eine ethnologische Studie zum Sterben im Altersheim*. Frankfurt a.M: Campus.
- Small, N., & Gott, M. (2012). The contemporary relevance of Glaser and Strauss. *Mortality*,17(4), 355-377. doi:10.1080/13576275.2012.730683
- Soom Ammann, E., Salis Gross, C., & Rauber, G. (2017). The Art of Enduring Contradictory Goals: Challenges in the Institutional Co-construction of a 'good death'. *Final Journeys*,24-38. doi:10.4324/9781315180137-3.
- Soom Ammann, E., Rauber, G., & Salis Gross, C. (2019). 'Doing death' the Mediterranean way: End-of-life in a segregated nursing home. *Mortality*,24(3), 271-289. doi: 10.1080/13576275.2018.1483906
- Sudnow, D. (1967). *Passing on: The social organization of dying*. Englewood Cliffs: Prentice-Hall.
- Waerness, K. (1987). On the rationality of caring. In *Women and the state: The shifting boundaries of public and private* (pp. 207-234). London: Routledge.
- Znoj, H. (1995). *Tausch und Geld in Zentralsumatra: Zur Kritik des Schuldbegriffs in der Wirtschaftsethnologie*. Berner Sumatra-Studien. Berlin: Reimer.