## 11 A convent initiative

Compassionate Community in Solothurn, Switzerland

Elisabeth Wappelshammer and Christine Weissenberg

Pre-professional forms of a supportive culture of care include competences that are at risk of going unnoticed. To answer the care needs of very old, frail and dying people, it is important to raise awareness of this kind of knowledge in order to develop integrated care models.

Where in our economised society are there models from which society can learn? A highly traditional model of caring is based on the monastic tradition, upon which we focused within the participatory research project, 'A Municipal Culture of Care: The Caring Community in Life and Death'. We combined the findings with the local and regional discourses of professional experts in care and medical treatment.

Similarly to other convents, the ageing community of the contemplative convent 'Namen Jesu' has succeeded in a striking manner in coping without professional help for many years. Our approach follows the thesis that relevant factors can be utilised for other actors in the care setting.

Beginning with an enquiry into coping strategies within the ageing community, the project aims at translating the findings into professional structures of old-age care as well as into civil–social structures. Our thesis is as follows: the successful integration of relevant aspects of our results within the discourses of long-term and ambulant nursing as well as in the culture of civil society, could mean that the culture of care changes in an innovative way.

Likewise, it must be assumed that traditional life in a convent cannot simply be replicated. Its origin is bound to special historical contexts, and social modernisation has also changed life within the convent walls. The value of insights from investigating the monastic tradition largely relates to the unfamiliar perspective regarding hitherto unquestioned aspects of current practice in treatment and care (Kreutzer, 2011: 254).

## The project in the national context of palliative care

According to our understanding, rather similar discourses take place in Switzerland as they do throughout the European context as a whole concerning palliative care. Here, too, professional health and care systems

are reaching their limits in terms of caring for old, chronically ill and dying people:

Services regarding hospice and palliative care are not yet reaching all those people who have need of them (Bundesamt für Gesundheit, 2012: 4). A representative survey by the Federal Office for Health (Bundesamt für Gesundheit, 2009) showed that 44 per cent of the participants would make use of palliative care in case of incurable illness, if this option were available. The vast majority (91 per cent) of the participants believed that palliative care should be available to all severely ill and dying people.

Some 75 per cent of the population would like to be able to die at home, yet more than 80 per cent are still dying in hospital or in long-term nursing homes. In fact, only 20 per cent of people die at home (with considerable regional differencies) or in another similar place.

- With rising life expectancy, the majority of people die after a long illness and phase of nursing, meaning that the demand for nursing and care is also rising (Bundesamt für Gesundheit, 2009: 3). Depending on predicted trends, the number of 80-year-old and older people living in Switzerland will rise from about 450,000 people presently to about 1,156,000 people by 2060 (Bundesamt für Statistik, 2013: 3). Last, but not least, the babyboomer generation will be reaching the final stage of life in the coming decades (Eychmüller and Cina, 2010: 221).
- A considerable proportion (approximately 60 per cent) of the population is cared for at home by informal caregivers, of whom about two-thirds are women and one-third are men, having an average age of about 66 years (Perrig-Chiello et al., 2010: 23). The outpatient and communitybased care requirements for patients and caregivers increase significantly.

## National palliative care plan

In 2009, Switzerland's health officials started a national strategy of palliative care, with a plan to run until 2015. The main objective is to achieve the widespread establishment of the palliative care concept and practice in Swiss society. The report and forward plan of the national strategy 2012-2015 in particular contain the observation that the number of annual deaths is increasing steadily and that care during the final phase of life is becoming ever more complex, not only medically, but also concerning psychological and spiritual needs. Moreover ageing populations increasingly desire a degree of autonomy and participation in medical treatment and nursing care.

Our project is dedicated to the framework of the national palliative care strategy plan - in particular at the level of cantons and local communities. Our participatory research approach includes the target groups of professional and voluntary experts at cantonal and local level. Moreover, a special focus concerns the ageing community of a convent.

## Critique of biomechanics-dominated approaches and the rationing of resources

Increasing critique can be observed in expert discourse, which requires a broadening of themes beyond pure medical questions regarding end-of-life care.

Here it becomes clear that issues at the end of life concern far more than pure medical or nursing competence according to the current, rather biomechanical definition. If the spectrum of subjects is limited, as the high number of deaths in hospitals and long-term nursing homes suggests, then great unease seems to arise.

(Eychmüller and Cina, 2010: 221)

This type of unease was confirmed by most of our interview partners who work as health professionals. Furthermore, they described what would actually be required: 'Certainly the best treatment of pain and other forms of suffering are a mutual partnership-based and respectful form of decisionmaking. This requires time, tranquillity, talks and preferably a clear head' (Eychmüller and Cina<sup>1</sup>, 2010: 221).

In particular, the limiting of care options in terms of 'end-of-life care' is perceived very critically where palliative care for people with long-term disease is concerned:

The point is that now the health insurance, or at least Santé Suisse, actually only wishes to finance end-of-life care. This now opens yet another interface. And we run quite a high risk of falling between two stools again, because we actually undertake palliative care. So, this is at the moment my focus within the palliative care network, that we emphasise palliative care and not end-of-life care, because the concept of end-of-life care starts too late for us. Now we have taken part in a pilot project, involving both our quality management and our performance measurement tool. Meanwhile, the insurers only want to pay for end-of-life care. In fact, they do not notice us, because end-oflife care is performed only for a matter of some months at the most. The work of an institution is only recorded if it does not last longer than 6 months until a person dies. What happens outside this timeframe is not regarded as end-of-life care. These are issues which weigh upon me very strongly. But we undertake palliative care in the truest sense of the word from morning to evening. And from my point of view this should actually be the issue. And finally there is again the problem of overprofessionalisation. It becomes technical again, new terminology is created again, and the human being is forgotten, always, always, always, always.

(Interview Graf, lines 160-177)

In Switzerland, assisted suicide is not a punishable offence, and is largely undertaken by organisations such as Dignitas and Exit. Within palliative care, this development is perceived and commented upon in very critical terms and is linked to the trend towards economisation and the dominance of cost-intensive medicine as well as the expense associated with nursing and care services:

The discussion surrounding assisted suicide seems to be a symptom for this unease, and in debates about costs, the issue of 'rationing' is always flashing up furtively. Here the issue should be more about the quality of medical indications and medical interventions at the end of life and less about the costs: A course of radiotherapy or a new stent within the last weeks of life are paid for by insurers without questioning the objectives or 'expected clinical benefit'. Care at home with auxiliary services and basic care provision is partly paid from the person's own private resources.

(Eychmüller and Cina, 2010: 221)

The management of a regional nursing home expressed a critical view of the tendency by health insurers to sometimes finance poor quality care and provided the following example: 'Treatment for a decubitus is paid for, but not the prophylaxis to prevent it occurring, which is rather care-intensive' (Interview Mathys, lines 16–23).

#### General situation in convents

As can also be seen in the Namen Jesu convent, monasteries and convents saw their last waves of entry during the 1950s and 1960s. This means that the scope of traditional monastic forms of living is decreasing, the communities are ageing and increasingly facing difficult decisions regarding the care of their frail brothers and sisters. Often the future of communities and their buildings is unclear, and old age is a central concern. The care that is required often cannot be performed any longer by the community itself and, in such cases, professional experts must be employed:

In the convents the 'nursing need of the sisters' must be looked at anew ... Through the changes in the age structure, the situation has changed drastically. We cannot carry out the care of our own sisters anymore. For many years we have had to recruit caregivers from outside. That means our care-dependent sisters are not cared for by their own community, which has led of course to big changes, both structurally and personally. There is not the usual family concern any more, the conditions of public health services must be fulfilled, etc.

This is a great challenge for the persons responsible of the cloister. Architectural, financial and structural questions must be discussed and managed anew. The challenge now is: On one hand the care-dependent

are concerned by this development, on the other hand, it also needs big efforts, for instance in-house training, so that the staff can understand how the structure of a convent works and can accept the traditions here. They must be aware that the nursing home is the home of the sisters

(Interview Juchli, lines 20–36)

A professional part-time nurse has also been employed in the Namen Jesu convent. Her integration in the everyday life of the convent has not been easy for both sides, because of contradictory expectations to some extent. On the nuns' side a completely new kind of leadership is required, with high levels of transparency, while the professional care service provider is faced with a culture based on historically acquired rules of strict discretion and partly on highly individual habits – far from any standards of quality management in professionalised geriatric care and nursing. For both sides, this can be very confusing and may cause real conflicts.

Monastic building structures are often many centuries old. In the case of the Namen Jesu convent there is much evidence of how little the architecture is appropriate for persons in old age, especially if measured against the norms and standards of geriatric care. Even if two lifts are installed, stairs and steps remain obstacles that are not manageable for all nuns or that at the least represent an athletic challenge. Yet this architecture constitutes the home environment for the members of the convent and guarantees continuity of time and social environment.

## Visions of change need unexpected and unfamiliar effects

Experiences with death and loss are inevitable. Public health discourses increasingly demand that this central field of human experience is given a central place in society (Kellehear, 2005). The challenge is to develop communities in which social cooperation and mutual responsibility are performed, with care provided both for the vulnerable dying and for those who care for them, and later mourn them. Adequate visions of change in the sense of a society in which a culture of care is regarded as centrally important are both challenging and complex – in particular connected to local and regional development of a culture of compassion and political concepts of care culture beyond standardisation and professionalisation. Which existing communities, however, can provide us with relevant examples?

In the Swiss convent Namen Jesu, we were able to make observations, carry out interviews and hold two workshops. After all, here too, death is visible. Slowly but inevitably even the model of cloister life is dying. Nevertheless, significant differences to other institutions can be observed. Illness and deficits in health terms seem to be not so dominant as in other settings. On the contrary, growing old seems to succeed with a great degree of grandezza, with or without dementia: 'Aging with Grace', as David Snowdon (2002) expresses it.

This was, in any case, the most surprising aspect of our observations; and astonishment and surprise seem to us actually to be rather beneficial effects, which can help find a way out from all too restrictive dynamics. In a situation in which most representatives of relevant professions and leaderships of administrative and political departments feel very much restricted by the current logics of care, which themselves hinder the formulation of desires for change and renewal, it is worthwhile to use perspectives that can offer the 'shock of the new'. The perspective of monastic life can achieve such impacts because the world behind cloister walls is shaped by a special mixture of old traditions and modern influence, in which the trends towards economisation, professionalisation and specialisation do not yet have so much influence as they do outside. Thus this form of care culture may be able to serve to open the door for generally required steps towards change that can put care at the heart of society.

## Development of the project

In the Name Jesu convent in Solothurn, largely self-directed care is undertaken in impressive fashion by the community itself. The elderly and very old nuns have managed extensively to cope without professional help and care up until now. For a long time a part-time cook has been the only professional nurse, albeit with another job description - helping with the cooking and building up confidence through working together. Everyday life is characterised by remarkable autonomy and dignity. But life has also become fragile, with the sisters increasingly needing help from outside. However, what happens when pre-professional and professional care encounter one another? Which care approaches used by the ageing community should be retained? What can professionals learn from this?

### Triangulation of methods

In terms of a productive connection between participatory research and theoretical discourse we focus on the question of which relevant aspects of discourses in palliative care can be identified in this kind of religious and spiritual community.

We describe the results of qualitative investigations by means of observations, interviews and workshops inside and outside the convent-Triangulation of methods was suitable for avoiding possible blind spots in our findings. Above all, participant observations helped in understanding aspects of monastic care culture, beyond the reflection of everyday culture in the interviews. In total, we carried out 13 interviews within the convent itself and within the setting of the Swiss convents and 16 qualitative interviews with professionals. Experts of professional care or medical treatment were also asked questions about their view of convents, as far as participants were familiar with them. In addition we conducted a workshop about the internal view of the convent and an interdisciplinary workshop with representatives of the convent, different professions and politicians as well as voluntary services.

## Challenges and learning effects

During the process of research in the convent we faced particular challenges:

- The first challenge was to establish the project in the convent altogether. The convent belongs to a contemplative community, the Capuchins, where silence and spirituality are regarded as central values. We assume that we only succeeded in establishing the project by taking part in the everyday life of the community, which gave us the opportunity to carry out participant observation and build necessary trust among the participants.
- The involvement with the monastic community, created by our integration in everyday life there, led to another great challenge. The growing needs of the community make it tempting for those coming from outside to interfere or even take on leading roles in some respects, as became clear while talking to some of our interview partners. We also had to realise through the example of the installation of a chair lift that we too were not free of this desire to help out in the context of convent life.
- Finally, it is necessary to understand modernisation in the context of cloister life - with principles like individualism and pluralism - just as we find it generally in society. The current model of convent life only in part reflects aspects of the original form of spiritual communities. Especially since the Second Vatican Council in the 1960s, reforms have taken place, and thus generalising about 'convent life' requires a differentiated understanding.

#### Results

## Coping strategies of the convent community

The following text introduces the life of a special community of a convent and its successful coping strategies from the viewpoint of living and dying in old age. In the analysis of the results of observations, interviews and workshops we combine our findings with analyses of Joan Tronto (2013) concerning a fundamental change, shifting care into the centre of society. How do coping strategies of this ageing community distinguish themselves from the perspective of the political scientist Joan Tronto? What would she perhaps perceive on a visit to the convent community?

Perspectives of carers and those being cared for

In democratic settings, both carers as well as those being cared for are involved. According to their area of competence, everyone takes part in the care culture.

In accordance with their vows upon joining the order, the nuns of the convent experience a fundamental attachment to each other, which goes far beyond personal sympathy. This determines mutual loyalty in everyday life, even if conflicts occur. The convent cannot be easily identified as a democratic setting, because beside democratic facilities, such as voting for the head of the convent and the debates in the council of the convent, the traditional culture of the cloister is characterised by a strong hierarchy based on the principle of obedience. Nevertheless, it seems that everybody is integrated on an equal basis into this community of care. Even if women themselves are ill and in need of care, they participate in the care of other sisters, if only through small gestures of support. Therefore it can be perceived that a nun who has fallen ill with dementia helps another sister who is mentally healthy but has physical problems using the stairs to the refectory. Above all everybody perceives the others as 'sisters' and it is clear that everybody has needs to care for, even those whose task primarily is caring. 'Human dignity happens when I am a human being to a human being, if I am a sister to the sister, respectively if the sister is a sister to the sister' (Interview Juchli, lines 300-302).

## Relational autonomy and dignity

At 94 years old, Sister Hildegard (pseudonym) is the oldest member of the convent and suffers from severe heart failure. However, she still maintain her position as convent custodian on a daily basis, refusing to give up this social role. She takes pleasure in using her 'Trottinette' (a push-along scooter) to travel the long corridors and laughs mischievously when others find her going along at full tilt, steering with one hand while holding her walking stick to push forward in the other.

Sisterhood seems to promote both relational dignity and relational autonomy. In the concept of relational autonomy, neither the dependence and autonomy of those who are in need of care nor that of their carers are ignored Both are autonomous as well as dependent. 'Dignity is socially constructed, individually perceived, embodied and relational' (Pleschberger, 2005: 37).

In convents, public life and privacy are complementary spheres, which nurture the dignity of community members as a manifestation of social life. Several times during each day, the nuns celebrate a (semi-) public life with one another, which serves a higher communal purpose and at times also incorporates guests from outside. At the same time, the option also exists for convent members to be able to withdraw into the intimate sphere of the closed community and their single cells.

In this culture, a highly beneficial balance is achieved between (semi-) public participation in the ritual phases of the day as well as experiences of community at work, spare time and meals on the one hand and intimate retreat on the other hand, as stipulated in the discourse around dignity in terms of 'acknowledgment' and relational dignity (Pleschberger, 2005: 28ff. and 113ff.). The everyday experience of the value of this balance means that the neoliberal idea that public care could be a danger for the whole community simply does not apply (Tronto, 2013: 144).

It seems that mutual care within the convent never intervenes further into the personal sphere than the community regards as necessary. Here care is regarded as serving an autonomous lifestyle, whereas forms of care that give those cared for the feeling that they are helpless are avoided.

The culture of 'sisterhood' means that the care culture also diverges from dyadic nursing arrangements, which generally dominate in the family context. Joan Tronto identifies dangers of caring dyads becoming an 'uncompassionate hierarchy', and she suggests that it is important to address the possibilities of a 'triangulation' of care (Tronto, 2013: 153). Even if a relationship between two persons involved in care does develop, in the convent there remains at least one other person responsible for the area of health care as a whole or other sisters may intervene where required, and there is now also a professional nurse from outside the convent. Thus the convent seems to be a place where the possibilities for 'triangulation' are more easily available than in families.

# On the production of 'others' - the cycle inspired by neoliberalism

A central aspect of political care culture is the neoliberal trend to produce 'others', whose apparent inability to assert themselves economically is interpreted as a decline of their personal value. As a result, annoyance, frustration and mistrust are nurtured on a wide basis, complemented by forms of political control and sanction (Tronto, 2013: 145). In such a culture, no broadly conceived culture of mutual care can develop. Neoliberal politics tends to produce a loss of personal value where there is a perceived lack of the appropriate success in terms of economy and consumption.

The nuns of the convent community have consciously decided to be 'others'. From the outset, the life of the relatively poor community is based upon embracing poverty and remains far away from the logic of the neoliberal economic system, which generates more and more needs together with social status, devaluation and exclusion. At the same time, a huge capacity for enjoyment can be observed in the everyday life of the nuns, which probably acts as the most effective cultural barrier against neoliberal dynamics.

## Inspiring networks beyond cloister walls

Although high and ancient stone walls surround the convent, various levels of contact with the larger community of the town and its citizens may be observed.

One of the key experiences during our research in Solothurn - both within as well as outside the cloister community - was that the concept of a 'culture of care' represents an inspiring catalyst for discourse within the relevant professional fields.

Nuns, volunteers and professionals who were active in the areas of outpatient, long-term and medical care embraced this concept. In the first instance it was professionals in particular who used it to articulate their critique of phenomena such as economisation, professionalisation and standardisation, which were seen as problematic issues. Despite or maybe because of the fact that the term is not clearly defined, it is capable of inspiring various actors to consider new perspectives and to express things for which the words were apparently lacking up to now.

Care culture: connections between convent, professional services and facilities, representatives of civil society, social administration and politics

How might the care culture of the convent ultimately provide inspiration for the world outside? One established connection concerns the local involvement of citizens who feel linked-to the convent community. They understand the lives of 'others' and feel a sense of personal attachment to the community.

Regardless of life within the convent, society has need of a culture of care which is based on the autonomy and dignity of every single person and offers the chance to participate actively, particularly during the last phase of life. The experiences of the Namen Jesu convent reveal a very old form of caring for one another in which strengthening the ability to care for oneself holds important value. This form of care deserves to receive attention in other social areas too and also from the organisations of social and health care systems, which still retain a paternalistic approach today.

In recognition of this, our research concentrated not only upon the convent, but included other stakeholders within the municipality and the canton of Solothurn: Doctors, in particular the founder of the cantonal palliative care network, the cantonal health department, an organisation providing outpatient care, a dementia-nursing centre, a hospice association, an outpatient service providing support for families caring for people with disabilities, outpatient hospice care, a canton-wide platform for volunteer work, a neighbourhood association, and last but not least, politicians.

In a situation in which most representatives of relevant professions, administrative and political departments feel severely restricted by operational logics, which themselves hinder the formulation of wishes for

change and renewal, it is worthwhile to make use of all perspectives that offer 'the shock of the new'. The convent Namen Jesu is able to provide such effects, because most of the nuns in the community are old and very old women and are often already so frail that one is surprised as an outsider that the community is still able to manage everyday life. Likewise every single one of the nuns exhibits a rather special, sometimes even wayward, form of autonomy and dignity. Especially impressive, however, is the way in which the cloister community deals with the resources, enabling them to also provide a service to people outside the convent, e.g. to women going through difficult phases of life. This creates a reciprocity of care, which is rarely observed in inpatient facilities for medical and nursing care.

However, those who are aware of the special complexity of this small monastic 'oikos' are thus also inspired to have their own thoughts about, for example, the establishment of a 'new care culture', outlined as a bottom-up strategy of a community-oriented life based on the idea of neighbourhood. Short-, medium- and long-term aims include, for example, care culture as a component of medical training at university as well as in school curricula and raising public awareness within the local community by stakeholders also in the sense of the principle of 'sister- and brotherhood' as a quality of a new care culture. Finally, the everyday life of the convent provides inspiration in terms of the rituals that permeate daily life, which contrast with the post-modern phenomena of growing alienation in spatial and temporal terms (cf. Rosa, 2013: 139ff.).

It was and is entirely clear to our partners in this participatory research process that the monastic tradition could not be transposed completely into other organisational settings, and even the nuns themselves regard such an idea either as inadequate or antiquated. But awareness and imagination are inspired to use central principles of this kind of centries-old explicit and implicit knowledge to benefit a contemporary culture of care - for example, concerning a good life in autonomy and dignity even as a very old and frail person.

Both the nuns who joined the final interdisciplinary and transdisciplinary workshop and the convent, as the location for this event, thus served as catalysts for new conceptual links concerning the local and regional structure of care and nursing and above all for a lively and fluid discourse. In this respect, one participant in the workshop coming from the medical sector commented on the role of religious communities as follows: 'These organisations are "infectious" and inspiring' (Cina, workshop report of comments, p. 6).

## Summary and outlook

As a first step, observations, interviews and a workshop were carried out within the convent, to determine the culture of care among a group of ageing nuns. In the second step, the local and regional potential of a new culture of care beyond the convent community was investigated with the help of interviews. In a joint workshop with all target groups, professionals and representatives of voluntary organisations, further ideas for the culture of care were developed, which can make a contribution to establishing principles of a new care culture based on solidarity with others.

In this way, the project generated comprehensive data, which are still available for further analysis regarding various themes. Likewise the participatory approach of the research facilitated the development of a network of interested experts together with members of the community at local and regional level. This network could be activated in a subsequent project to continue, intensify and widen the discourse about a new culture of care.

#### Note

1 Christoph Cina was one of our interview partners.

#### References

- Bundesamt für Gesundheit BAG/Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und –direktoren (GDK) (2009) Nationale Strategie Palliative Care 2010–2012, Bern.
- Bundesamt für Gesundheit BAG/Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und -direktoren (GDK) (2012) Nationale Strategie Palliative Care 2012–2015, Bern.
- Bundesamt für Statistik/BFS (2013) Zukünftige Bevölkerungsentwicklung.
- Eychmüller, S. and Cina, C. (2010) Licht im Dunkel für die letzte Lebensphase –was bietet Palliative Care? *PrimaryCare* 10(12): 221–222.
- Kellehear, A. (2005) Compassionate Cities. Public Health and End-of-Life Care. New York: Routledge.
- Kreutzer, S. (2011) Glaube als biographischer Rückhalt im Umgang mit Krankheit und Sterben. In: H. Remmers (ed.) *Pflegewissenschaft im interdisziplinären Dialog. Eine Forschungsbilanz.* V&R unipress, Universitätsverlag Osnabrück, S. 239–257.
- Perrig-Chiello, P., Höpflinger, F. and Schnegg, B. (2010) *Pflegende Angehörige von älteren Menschen in der Schweiz*. Schlussbericht: SwissAgeCare.
- Pleschberger, S. (2005) Nur nicht zur Last fallen. Sterben in Würde aus der Sieht alter Menschen in Pflegeheimen. Freiburg i. B.: Lambertus.
- Rosa, H. (2013) Beschleunigung und Entfremdung. Frankfurt a.M.: Suhrkamp.
- Snowdon, D. (2002) Aging with Grace. What the Nun Study Teaches Us about Leading Longer, Healthier, and More Meaningful Lives. New York: Bantam Books.
- Tronto, J.C. (2013) Caring Democracy. Markets, Equality and Justice. New York New York University Press.