Self-neglect and End-of-Life Care – A Conceptualization in View of the Idea of Stigma

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Self-Neglect (SN) is a controversial term, as it mainly describes an individual deviation from the socially desired normality (cf. Goffman). In this effect, emphasis is regularly put on chaotic/ neglected home environments or housing fulfillment. Many research studies concentrate on elderly SN, only few broach other issues (e.g. potential relations to psychiatric disorders and other causes, ethical and legal questions). The exact number of people affected is unknown. Nevertheless, many social and health care professionals from different settings describe an increase in the number of people affected. They also feel that dealing with these people is particularly stressful and challenging. In the context of End-of-Life (EoL) care SN is important in two ways. First, we need to deal with neglect as a relevant subject, when we claim to facilitate EoL care to all persons in need. Second, EoL care may contribute to an approach addressing SN. Bases on literature about SN we describe this concept, including Goffman’s stigma term and the correlated stigmatization process, and discuss it in terms of the understanding and values of EoL care provided in hospice and palliative care (PC).

The Concept of SN

SN is often described as a syndrome with different manifestations and causes (Figure 1). It includes physical, mental and social neglect caused by vulnerable, physical, as well as psycho-social challenging, life situations and appears in different intensity and consciousness. Some affected people (knowingly) decide to life e.g. in a chaotic home environment, but many are not aware of their situation. Additional SN is described as symptom of different psychiatric disorders.

The description shows that SN is always observed, described and defined from a certain perspective. The society or its representatives look out of their intended normality to more or less serious deviations. All definitions, as well as the term itself, are therefore normative. The self-image of those who live in a “self-neglected” life situation plays a minor role, as their adaptation behavior to counteract the pressure does. Hereby the idea of stigma is connected.

Figure 1: Self-neglect

EoL Care services

EoL care is seen as support for people who are in the last period of their life. Part of EoL care are hospice and palliative care (PC). PC wants to improve “the quality of life of patients and their families facing the problems associated with life-threatening illness” (WHO). Besides many other interventions hospice and PC both include company and counselling during and after a persons EoL period. According to the differentiation of stigma, EoL care seems to include a stigmatisation processes concerning the terminal illness but also sorrow as part of bereavement. Values connected to EoL care also seem to incorporate those perspective and reinforce it with ethically assumptions. But closer inspection shows different:

- The overall aim of social and health care professions is to involve vulnerable persons into the ethics’ scope, so that they experience protection and participation. It is strongly connected to discussions about autonomy and justice, focussing on health care as dignity constituting (face-to-face) encounter.
- EoL diversity as a special aspect of EoL care can be understood by the fact that the situations of the involved persons are fundamentally different. One person dies and leaves the world for good, while the others remain. This asymmetry cannot be overcome and the special life situation of a dying person cannot be understood by remaining others. Another asymmetry is that dying is not a disease, but is mostly accompanied by life-limiting diseases and medically treatable symptoms. As a result, although the person passes away, only the patient (guest/resident) may be treated. Treatment, company and counselling need to be individual. But they all never repeal EoL diversity.

SN and EoL care

Regarding SN in the context of EoL care the following core aspects occur:

- Based on the idea of stigma and its differentiation SN and EoL care can be understood as stigmas provoking unequal reactions.
- Core aspect of the interaction with affected persons is the reflection of one's own values and expected behavioral concepts. In a second step, professionals and other team members should adjust their behavior, especially their reactions. Even though this may be challenging and personal limits should be observed, ethical assumptions support this.
- The self-determination of those affected has to be respected. They need to be involved in decision making and care planning. At this point EoL care may contribute as it justified by special values focussing on autonomy and individual quality of life, the awareness of EoL diversity and includes special (professional) resources like supervision and communication skills.
- The high complexity of SN requires an interprofessional team using overall existing structures. That could enable more, so far untreated, persons at the EoL to gain access to hospice and PC. Research in other stigmatized groups supports this assumption.
- Further research is needed to address the access of affected persons to EoL care services as well as possible low-threshold intervention offers, including individual and non-stigmatization face-to-face interactions. EoL care may contribute to this process. Therefore, it needs to reflect its own potentially stigmatization habit/ basis to prevent the exclusion of people showing deviant behaviour.

Stigma and stigmatization

Today's stigma research uses the term stigma according to E. Goffman. He describes stigma as an attribution made by actors in the context and frameworks of social (face-to-face) interactions: *"While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one."* (Goffman 1963: p.11) Based on his assumptions about social interactions and their identity-forming effects he highlights the particular impact of normative expectations introjected by socialization which influence our interactions with other people (Figure 2).

Figure 2: Interaction - identity and stigmatization

Other researchers referred to this idea of stigma and differentiated different types of stigma. This process connects the underlying (discrediting) interaction, with its influence on the individual identity and possible dilemmas of those affected. In this context it becomes apparent, that interactions with stigmatized persons seem to be guided by a differentiation of stigmas related to its on-/ offset and other connected factors like responsibility or expected controllability and reversibility. Overall, onset-uncontrollable and irreversible causes of stigma lead to help-giving reactions whilst onset-controllable and as reversible assessed causes result in convicting behavior. Both reactions are problematic, because they manifest stigmatization instead of reducing it by individual relations and interactions.