Life story methods and care for the elderly.

An empirical research project in practical theology

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ABSTRACT

The focus of the research project presented in this article is on the structure of the life stories of elderly people living in old age homes and its relationship to well-being or quality of life and the quality of the caring relationship. In an experimental design, we are testing the hypothesis that intervention with narrative methods has a positive effect on existential well-being and quality of the caring relationships because of the impact it has on the quality (content and structure) of the life story. We used a specific narrative intervention called the Life Book method in an experimental group of 70 elderly people and provided extra attention to a control group of 30.

The theory of narrative identity (Paul Ricoeur) offers some building blocks for developing a tool for assessing the process and structure of the life story and its impact on existential well-being.

This project is conceived as an effort in practical theology in the public square. Its particular perspective is that of spiritual care, which is located on the intersection of two social spheres: health and worldview. Possible outcomes are described (including an expected corroboration of our hypothesis (strengthening the caring relationship on micro- and meso level) and contributions are indicated to narrative theory, theory of care, practical theology and spiritual care and counseling.

INTRODUCTION

It is hardly innovative to speak of the narrative quality of human existence (Sarbin 1986). Perhaps it never has been, given the fact that stories have always been quintessential in our understanding of ourselves and of the world we live in. It is this storied nature that is also most prominently present in religion, making it an

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important approach in practical theology as well (Ganzevoort 1998). The fact that it seems new stems from the fact that in the western culture attention for the narrative dimensions of life has long succumbed to other kinds of rationality.

Stories are vehicles of identity. We shape, transform, defend, and pass on our identities through our stories. This goes for individual life stories in for example pastoral conversation, as well as for the collective stories of communities or even cultures in economic myths and the stories of the commercial media. This function of the stories as vehicles of identity does not mean that the identity that is expressed can be isolated from the story. Rather, our identities themselves are understood to have a narrative structure (Ricoeur 1988). This underlying – and by definition implicit – narrative identity is a key element in theories on identity and stories. It is hypothesized to reflect and influence our social and psychological functioning.

In various domains and for different groups, narrative methods are developed for professional attention to identity. From psychotherapy (Freedman and Combs 1996, White and Epston 1990) and pastoral counseling (Müller 1999) to education and care for the elderly (Mies 1999), narrative methods evolve that are thought to offer a unique contribution to the development or sustenance of identity. Professional and family caregivers usually welcome the use of narrative methods because of the explicit attention to the individual and psychosocial dimensions. Moreover, narrative approaches incorporate dimensions of worldview, spirituality, and religion in a very natural manner (Ricoeur 1995).

There is, however, an inherent conflict between the narrative perspectives and the medical and organizational rationality of the health care systems – the context in which the presented research project is executed. Although the medical system more and more addresses the narrative and existential dimension, the predominant rationality is still technological. Given the ever-increasing costs of the western health care system, an economic rationality is superimposed in which only those treatments are offered that are evidence-based, effective, and efficient. In both of these dominant perspectives there is little room for the supposedly time-consuming narrative methods with their existential orientation. Accounting for this conflict of perspectives, this research project seeks to measure and explain the effects of life story work methods. The focus of our research is on the structure of the life stories of elderly people living in old age homes and its impact on their well-being or quality of life and the quality of the caring relationship following a specific narrative intervention called the Life Book method.

In this article we present the research design. We first describe the perspective (spiritual care), context (elderly care in the Netherlands), and key concepts (identity and well-being). Then we introduce the narrative intervention instrument and the research design. Finally we will address the possible outcomes of this project. More specifically, the relevance of this project and implications for practical theology and spiritual counseling will be discussed.

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CONTEXT AND KEY CONCEPTS

This project is conceived as an effort in practical theology in the public square. Its particular perspective is that of spiritual care. This perspective derives its particulars from the extra-congregational contexts in which it is performed (the military, penitentiary institutions and health care institutions). Distinguished from ecclesial pastoral care (with its more explicit Christian frame of reference), the profession of spiritual care is located on the intersection of two social spheres: health and worldview. The primary worldview involved is that of the receivers of spiritual care, not of the caregiver. The spiritual caregiver has to deal with different worldviews when providing guidance to people whose troubles arise in the context of ultimate meaning and concerns. The formal goal of spiritual care is communication on worldview issues, while its ultimate goal relates to the contribution of health, including spiritual health or existential well-being.

Although spiritual care is being developed as a particular profession, much work in this field is actually done by other professions, first of all by nurses. The spiritual competence of nurses has therefore begun to receive attention of researchers. Consensus is growing that health care is best organized as an integrated enterprise in which the spiritual dimension is taken as seriously as physical and social dimensions. In our view, this implies that health care institutions should appoint professional spiritual caregivers, but it also means that other health care professionals should incorporate attention for the spiritual dimension. It is for that reason that this project focuses on a method that can become part of generic nursing skills.

The specific context we locate our research in is that of elderly care in old age homes. On a population of 16 million, more than 2 million people in the Netherlands are older than 65 years and their number is growing. Although they tend to live in their own homes as long as possible, supported by a large network of social, medical and welfare facilities, at a certain point in time many of them need an institutional living environment. Our focus is on 'old age homes', designated for the elderly with reasonable health but in need of general daily care. Notwithstanding the low degree of religious affiliation – only one in three adults is affiliated woth a church (Bekker and de Wit 2000) and even of members (Protestants, Roman Catholics, and Muslims) an average of only 12% attend church or mosque once a week[2] – spiritual care in these homes is formally supported by legal regulations: it is understood that the freedom to exercise one's religion implies that spiritual care is provided for those unable to participate in regular religious structures (as is the case in the army, prisons, and health care institutions). Still, in only 15-20 % of old age homes, a professional spiritual caregiver is appointed. This can be seen as an indication that care for the spiritual well-being of elderly residents needs more attention, not least because there is ample evidence that adequate spiritual care has an impact on other parameters in

[2] See: http://www.cbs.nl/nl/publicaties/artikelen/algemeen/webmagazine/artikelen/2002/1094k.htm. Figures apply to 2001.

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the domain of the well-being of people (Koenig 1999, Levin 2001, Plante and Sherman 2001).

The key concepts in our research are narrative identity and well-being. We already alluded to the Ricoeurian notion of narrative identity, the understanding that human identity corresponds with the structure of a narrative – thereby characterizing identity as a dynamic process. Ricoeur identifies narration amongst doing, speaking, imputing and naming God, as a human activity. Hence he combines action and narration and holds that every narrative has a temporal coherence whereby the so-called plot (the organizing principle that interrelates actions and events in human life) links past, present and future to one another. Narratives have a certain coherence between these dimensions of time and a set of goals that people pursue (e.g. standards of excellence, like being a good parent). Narrative has a connection to life – from birth to death – and is reconstructive and open.

With specific regard to narrative identity, Ricoeur identifies three structural components: historicity, sociality, and praxis. As regards historicity, he discerns a dialectic of continuity and discontinuity (reflected in the views of self as idem versus ipse). In sociality he sees a dialectic of self and other, expressing the ethical nature of identity. As for praxis, he describes the dialectic of activity and passivity, referring to the self-constructive and receptive aspects of identity. This theory of the narrative identity offers some building blocks for developing a tool for assessing the process and structure of the life story and its impact on existential well-being.

In this research project we will test the hypothesis that the intervention with a narrative method focused on the individual life story of the elderly person will have a positive effect on existential well-being and quality of the caring relationships. This hypothesis is based on the common experience of workers in the field of institutional elderly care that life story methods have a beneficial effect on well-being and the caring relationship and as a result on the quality of life of elderly residents. To date there is neither empirical evidence of this effect[3], nor an adequate explanation. Therefore, we will also explore the explanatory hypothesis that this effect can be understood through the impact of the method on the structure and content of the individual's life story. For policy makers on the local and national level, this evidence is required, especially in a time of limited financial resources. Our aim then in this project is to describe and explain the effects of life review methods on well-being and caring relationships. We will render the research design following a description of the intervention instrument.

[3] Effect research has been conducted for validation, reminiscence, and other approaches in working with people with dementia. Typically some improvement of communication was found (Dröes, et al. 2004).

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THE INTERVENTION INSTRUMENT: LIFE STORY METHODS

The research project circles around a narrative intervention suitable for elderly care. As indicated earlier, a broad spectrum of life story or narrative methods can be identified in this domain. Mies (1999) identified 23 approaches in her research on life story methods in the care for the elderly. She groups these methods in four clusters: reminiscence, life review, autobiography and life history.

The first group, Reminiscence, regards a process of recalling experiences and events memorable for the individual. It is regarded as a 'light intervention' whereby the caregiver or therapist stimulates the client to recall positive memories and tell about the times gone by. The accent lies on either the whole or a part of the client's life history. Reminiscence has a spontaneous and associative character. It is important that the client experiences this intervention positively.

Compared to reminiscence, Life Review – as the second group of identified interventions – is a more formal and structured intervention that can be defined as an overview of somebody's existence in retrospect. It is a critical review of somebody's life or a second glance on somebody's life. The full lifespan of the client is brought into play whereby he/she looks back in a structured manner. Central to this intervention is the element of evaluating life, thereby connecting and combining both negative and positive life experiences with one another into a new whole. Life review is seen as a 'heavy intervention' that expects from the elderly person to relabel and revaluate earlier experiences in a more positive way.

The third approach, Autobiography, is defined as the history of a life story, written by the person who has lived and experienced that life (Birren and Cochran 2001). The main feature of this intervention is the description of (parts of) the life story. It is a structured activity which encompasses the most important life themes and is directed towards both positive and negative memories. The writing of the autobiography – in which the initiative lies with the client – does include an evaluation, but it is not regarded as therapy. This method is, like the life review, characterized as a 'heavy intervention' due to the structured approach.

Fourth, Life History is a client centered case study in which the caregiver or therapist makes use of the life story of the client. Although it is important that the client enjoys telling his/her story, it is not the main purpose of this method. Caregivers use it to get to know the client better with the purpose of optimizing care or therapy. The Life History intervention is typified as 'average' with regard to 'invasiveness'.

The difference between these four methods lies in the kind of memories they try to recall, the scope they cover in glancing back on somebody's life and the extent to which spontaneity, structure and evaluation are incorporated. We have seen, e.g. that the evaluation aspect is less penetrating in the Reminiscence intervention when compared to Life Review and Autobiography. With Life History evaluation serves a subordinate purpose. This is because Life History's only purpose is to generate information as a means to proper interventions in care and therapy,

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while Reminiscence, Life Review and Autobiography, being interventions themselves, purposefully generates a process in the client. However, it remains difficult to make a clear distinction between these life story methods.

For the purpose of our research we decided upon an intervention closely related to the life review approach, called the Life Story Book method. The 'product' of this method is a life book which contains stories and valuable and memorable photos, letters, poems, objects, etc. which are metaphorical for persons and events in relation to the individual him/herself.[4]

The reason for opting for this method lies in the observation that the life book intervention can serve as an integral and structural part of regular care in nursing homes, to be implemented by trained nurses and not necessarily by professional therapists. The elderly person gets the opportunity to review his/her life with a nurse and a volunteer (e.a. a family member) along the lines of six life themes. Each theme is addressed in one of the weekly meetings with the nurse, resulting in a 'chapter' in the life book. The volunteer aids in bringing together material to include in the life story book, but the choice of the order of themes and of the content for each theme is made by the narrator him-/herself. For each theme, we have compiled a set of subthemes and questions that serve to trigger stories.

The first theme is the chronology of lived life. Here the whole life history of the respondent is charted along its main lines. Life will be divided into different periods form birth to the present day and the different periods are given specific titles. The narrative issue at stake is the temporal ordering of the story, in which certain life periods gain more attention than others. Thus it is no coincidence that the life period of adolescence and the historical period of the WWII attract quite a few stories.

The second theme regards important relationships. The participants are invited to make an inventory of the most important people in their lives, both in the past and in the present. Special attention is given to typifying the person-in-relation. The narrative category is role attribution, and it is understood that a person's narrative identity is reflected not only in the first person's role in the story, but by the complex interplay of roles (Hermans and Kempen 1995).

The third theme is lifework. The subject here is the achievements in life. The participant is asked to talk about education, career, vocation and responsibilities, and hobbies. The objective is to formulate a motto by which their lives can be characterized. In narrative terms, this is related to the aim of purposeful life (McAdams 1990)

The fourth theme is growing old and the meaning of life. The intention is to reflect on the meaning of growing old. Is growing old an expression of the art of

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[4] Related methods use 'memory boxes' or little suitcases in which the objects and narrative elements are ordered spatially. For purposes of comparability, we limited our project to 'books'. The specific version of the Life Story Book Method used in our research was developed by drs. Wout Huizing (Reliëf) en drs. Thijs Tromp (Reliëf/ThUK)

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living, and/or is a favor for which the person should be grateful? The conversation will deal with questions about finitude and the support systems the respondents identify in their lives. In narrative terms, this refers to the actual lifeworld of the participant and to a sense of closure of the story.

The fifth theme is that of norms and values. Here an assessment will be made of people's faith in life. Can they name moments of resistance and surrender? What is the meaning of it and to what extent can they distill anchorage from it? The narrative issue here is the inherent existential and even transcending meanings of all praxis.

The sixth and final theme is called a profile of the self. In this last session, with both the family member and caregiver present, a profile of the person will be made which will reflect the 'golden thread' of 'unfolding tapestry' of the person's life (Fowler 1987). One will look back to the past and forward to the future, trying to identify a metaphor or title for describing one's life.

Working with these six themes (and a wildcard for idiosyncratic topics), the intervention lends a formal structure to the conversations, but both the actual content and the order of themes remains the choice of the participant. The cards of the chosen theme are given to the elderly person so that he or she can think them over in between sessions, and the exchanges themselves are open and unstructured. The aim of this method is to generate more than a mere recalling of memories. It wants to enable the elderly person to discover his/her own 'multi-voiced self', thereby entering into a process of learning to know him/herself anew. Hopefully the elderly person will be able to describe the purpose of his/her life and anticipate on the (near) future.

When compared to the four groups of life story methods, the Life Story Book intervention resembles to a great extent the Life Review method. The exceptions lie in the 'openness' of the structure of the interviews, the 'openness' of the 'product' (the life book has an open end, because it underlines the uniqueness of each life story) and the 'executioners' of this method (professional therapists vs. nurses, volunteers and family).

RESEARCH DESIGN

In our experimental research design, this Life Story Book method is the central intervention. We have recruited an experimental group of some 70 and a control group of around 30 elderly people from eight different old age homes (as the project is still in progress, the final number is not yet known). The intervention consists of a six-week program in which the participant creates a life story book together with an assigned nurse, trained for these purposes, and a caregiver from the family or direct social context. The participant and the nurse meet weekly for an hour and a half and work on the themes specified in the method. The control group receives alternative attention by an activity leader or volunteers, to control for the dimension of attention.

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Before the intervention (T0), immediately after the intervention (T1), and five months later (T2), all participants complete a questionnaire with items about well-being (Marcoen et al. 2002), and about the caring relationship. In addition to that, a brief very open narrative interview is conducted with only a few open questions to trigger the storytelling. Parallel to these interviews, for each participant the nurse and the volunteer-caregiver complete questionnaires about their motivation and satisfaction in the caring relationship.[5] In the analysis we try to establish the unique effect of life review methods, controlling for attention and the lapse of time.

The explanation for the effect will be sought in the quality, content, and structure of the individual's life story as measured in the narrative interviews. We hypothesize that life story methods may influence the life story in terms of enhanced integration, differentiation, and flexibility (Hermans and Hermans-Jansen 1995). That is to say, we expect that the intervention will help individuals to tell a more coherent and meaningful story that allows for the ambiguities of life. This means that the immersion in narrative work adds to the narrative competence of the participant. Based on several theories of narrative and personality, we will analyze the interviews for indicators of change in structure and content (Hermans and Kempen 1995). We will for example analyze the number of themes that are addressed in a story and the degree of relatedness, issues of perspective taking and role distribution, and the ways in which positive and negative evaluations function in the story (Ganzevoort 2002). This large scale narrative research (with 100 participants and 300 narratives) gives us the opportunity of relating narrative changes to the possible changes in well-being of the elderly and in the caring relationship. As part of the project, we will relate these dimensions of narrative identity to theological issues around the meanings of life.

A final element of the design is a monitoring procedure for the implementation effects for the institution. These effects, measured on the level of the elderly and on the level of the nurses, will be coupled with an interview with the managers to assess organizational consequences.

POSSIBLE OUTCOMES AND IMPLICATIONS

In conclusion, we shall briefly discuss the possible outcomes and implications of this research project. This will be done on two levels, practice and theory.

Firstly, the level of practice: Given the many testimonies from the field, we expect that the intervention will – on the micro-level – indeed yield a positive immediate effect on well-being and caring relationships. We anticipate, however, the possibility that the immediate effect on well-being may be negative if the intervention helps participants focus on negative life experiences. We are uncertain about the effect after five months. There is some reason to believe that

[5] Questionnaires were developed by dr. Moniek Steggerda (KASKI) and drs. Thijs Tromp (ThUK/Reliëf)

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the effects may be temporary. We base this intuition on experiences from the field and on the hypothesis that it is the process of working together that accounts for the changes. However, we try to isolate the effect of the narrative method by controlling for extra attention.

Furthermore, we expect professional and family caregivers to develop increased motivation for partaking in enhancing feelings of well-being of the relatives, but for the professional caregivers this may be balanced by the lack of time they have to do their job properly. This has implications for the meso-level. We anticipate that the positive experiences will only be found if the institution can allow for more interaction time between caregivers and the elderly. Therefore we expect a correlation between the quality of care-measures and the organizational commitment to this type of integrated care.

Finally, and related to the meso-level, we expect that health care institutions will benefit from the implementation of methods like this in terms of employee satisfaction and residents' well-being. This may even result in a somewhat reduced demand on care or even a reduction in employees' absence due to work-related factors. We do not expect, however, that the economic benefits this might create will outweigh the investment of time and money. The question whether this intervention will be implemented as a structural part of regular institutionalized care to older residents and the implications thereof for professional spiritual care giving might therefore remain open.

Secondly, the level of theory: We think here of the relevance of the explanation of the effects of the intervention for theory. We expect the theoretical implications to be related to four areas: narrative theory, theory of care, practical theology and spiritual care and counseling.

In the field of narrative theory, this project is an important contribution to the theory of life story methods. Given the fact that we have a large sample for narrative analysis, this project represents an important step in the development and validation of measures for the quality of life stories. The connection between the analysis of narrative structure and content on the one hand and well-being and quality of care on the other, is a major innovation that bridges the gap between 'soft' approaches like narrative and 'harder' data from the psycho-medical realm. These implications and possibilities define the technological relevance of the project.

As for content of the study, we expect a correlation between the intervention and an increase in personal well-being on the side of the respondents. The theoretical implication would be a corroboration of insights from narrative therapy that these approaches not only influence the way a person tells his or her story, but also impacts the person's attitude and experiences. If we cannot establish this effect, narrativists' claims to this respect will be challenged.

In the field of theory of care, the expected outcomes of the project might critique the conceptualization of the concept of care in institutionalized health care. The anticipated increase in the measured quality of the relationship between resident,

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caregiver and volunteer might be labeled as an increase in the quality of the caring organization. Because the intervention and procedure explicitly address the relational and spiritual dimension of being human, this requests a widening the scope of the contemporary care-concept used in practice. This would be in line with Tronto's notion that adequate and loving care in a specific situation will evoke a caring response congruent to it (Tronto 1993, Verkerk 1994). The caring response is inherently related to the quality of the caring relationship, which refers to the centrality of humanity in human (co-) existence. Hereby a contribution might be made to nursing theory in the Dutch context. The care concept is expected to be broadened whereby nursing assessment theory will be benefited, because of the inclusion of spirituality as an essential dimension of anthropology.

This ethics of care approach connects to a fundamental liberating intention of our practical theological research project. The focus on life stories and well-being of the vulnerable group of elderly people s intends to help accomplish that they receive more personal attention and are facilitated to voice their own story. On a more general level, we can say that the project intends to contribute to the preconditions for qualitatively good care, including professional spiritual care in nursing homes.

This project reflects central intentions of our view of the field of practical theology and spiritual care and counseling. For starters, the project is an effort in public theology. In the Netherlands, it is almost a novelty that theologians are invited and funded to participate in research in the field of health care. Engaging in projects like this is part of our responsibility for engaging in and reflecting on (the need for) public theology. The formation of a public theology based on the outcomes of this project might be related to the notions of diaconia, healing, faith, religion, the Kingdom of God or the ultimate environment (Fowler 1981), salvation, and liberation. Our expertise in narrative, meaning, and spirituality is brought to the task of interpreting life stories and improving care in health care organizations. For our practical theological interest, the investigation of implicit religion (Bailey 1997) serves us in analyzing theological issues beyond the traditional realms of religion.

Perhaps even more than in practical theology per se, this project fits in the evolving discipline of spiritual care in health care contexts. More and more, this is an acknowledged profession alongside other medical, para-medical, nursing, and psycho-social disciplines. As a profession, the key concepts are described in functionalistic terms like meaning and view of life, while traditionally pastoral care is described in more specific substantial terms derived from the Christian tradition. It is a matter of debate how pastoral care and spiritual care should be defined in relation to one another. At any rate, this debate signals the need to reconsider our concepts because of the secularizing and pluralizing tendencies in which exclusive and explicit commitment to one particular religious tradition is bothersome. The project at hand, focusing on fundamental notions like integrated care, relationship, humanity, human well-being and view of life, is a contribution to this developing discipline. It might also lead to enhance reflection on the

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grounding of the legitimacy of professional spiritual care in health care and also on the attention given to spiritual needs of people admitted to health care institutions. The data might add invaluable information for supporting the notion of humanizing health care and challenging the evidence-based rationality of current medicine.

We see practical theology as the hermeneutical analysis of lived religion. That is, our task in practical theology, including the theory of spiritual care lies in the observation, analysis, and evaluation of the praxis of life view, religious faith, and meaning. This praxis is precisely the matter of investigation in this project. The life stories we investigate center around the evaluations of life and the meanings attributed to it from the perspective of the individual view of life, which may be religious or secular. Our central interest as theologians is in these 'narrative characteristics' of the 'lived life' of individuals. Not only for the general theory of practical theology and spiritual care as such, but also for the theory of (pastoral) care and counseling the findings might have exciting implications. Future steps will include the study on the phenomenology of 'narrative coping' and the role spirituality or faith plays in it (Ganzevoort 1998a, 1998b).

CONCLUSION

This presentation of the research project 'Life story methods and care for the elderly' has highlighted the context and background, design, and possible implications of the project. Although not explicitly theological in all respects, we claim that it fits into an approach that views practical theology as the theology of praxis and that it is highly relevant for not only the field of elderly care, but also the disciplines of practical theology, spiritual care, and health care ethics.

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