



'Grasping or letting go?' Reflections on 'inner space' of patients in palliative care

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Introduction

Studies on the patient's perspective in palliative care often use words as needs, wishes or satisfaction. That is helpful, but includes a reframing of patient experiences into a language with which professionals feel comfortable. A focus on experiences and concerns of patients as expressed in their own 'language' might enlighten the essence of these experiences and enable a support of better quality. Analysing the *discourses* that patients use verbally is a methodological way to come to a better understanding of how they cope with the approaching death.

In The Netherlands an important newspaper (*NRC Handelsblad*) published a series of interviews called 'Het laatste woord' ('The last word') on a weekly basis during two years (March 2011- March 2013). The 108 interviews by Gijsbert van Es describe the art of living when approaching death.

Interviewees tell in their own words what they experience in the last phase of life; some relevant pictures or symbols were added. When the series was finished readers asked for prolongation of these weekly interviews.

This study wants to enlighten patients' perspectives in the last phase of life in their own discourse. The central question of this project was: **What is the phenomenologically identified essence of their experiences?** What does this mean for the nature of help offered?

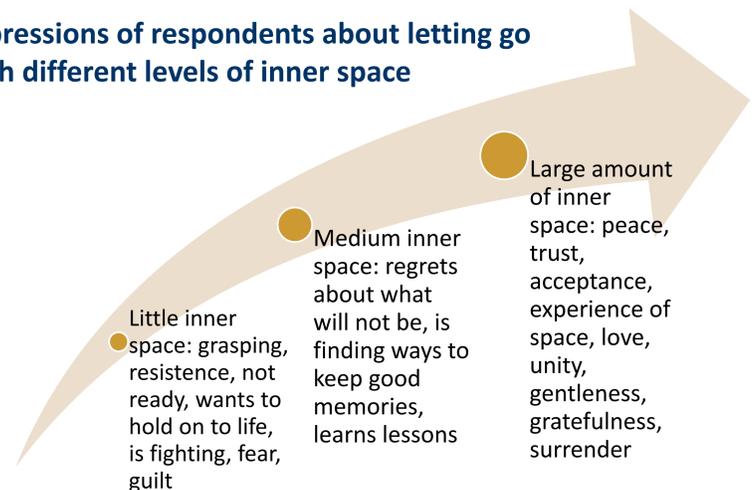
We performed a phenomenological analysis based on 40 'The last word' interviews. These selected interviews were read intensively, coded and cross coded. The three researchers double checked their interpretations and conclusions.

Results

The analysis showed a phenomenological identified core category of a central process of grasping and (gradually) letting go. After the first shock patients felt more intensively connected to what really counted in their lives, what made them feel themselves or dignified. This could be the attachment to children, spouses, nature, art or philosophy. Sometimes wishes about the future appeared very difficult to let go of. Respondents tried to manage their situation by letting go of these self-acknowledging connections, images and wishes in different ways. Some patients offered no resistance. They were able to accept and have peace with their dying, while others experienced an intense existential struggle and suffered. For many of them moments of peace and struggle alternated. As one respondent said: "Two goals can be set: to refrain from cherishing wishes and to reconcile with the past. I rarely succeed in this." Respondents performed inner work in trying to handle this. This process of managing the letting go could be recognised in all stories.

We interpreted differences between patients in managing to let go from three different theoretical perspectives: psychological coping theories; the psychiatric stages of grief (Kübler-Ross); ars moriendi traditions and the concept of inner space (Leget).

Expressions of respondents about letting go with different levels of inner space



The inner space concept matches the discourse of respondents best. Inner space concerns the attitude towards existential and spiritual issues in life. It can not be easily understood from psychological or psychiatric frames or language. It is 'a state of mind that enables one to be aware of one's actual thoughts and feelings without being overthrown or swept away by them' (Leget, 2003). Recognition of inner space as a valuable concept to understanding patients' situations at the end of life, enlightens questions about possibilities to support patients to maintain or enlarge their inner space. For instance volunteers may play an important role in the identification of what helps patients to hold on to their inner space or to enlarge it.

Implications

Based on the results, input for reflection sessions of volunteers was designed. Coordinators of volunteers might use this material for creating moments of reflection with volunteers in palliative care settings and improve their skills to change perspective. The core of reflection was recognizing what it means to have to let go, recognition of different theoretical perspectives to understand letting go and identification of what might enlarge the inner space of patients.

Literature

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