



Patient education as a status passage in life – An ethnographic study exploring participation in a Danish group based patient education programme



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ABSTRACT

In this paper, we apply the theory of status passage to the empirical field of group-based patient education. On the basis of ethnographic fieldwork carried out in the context of a local Danish patient education programme aimed at people diagnosed with rheumatoid arthritis, we illustrate how participation in the programme for the recently diagnosed is a regularised status passage symbolising a transition in life from a novice to a more experienced person with chronic illness. We demonstrate how central properties of status passage are at play and how they are shaped by interactions among the different agents: participants, lay experts and health professionals. We highlight how the unique biographical situation of the individual and the individual timing of participation is an important factor affecting whether the patient education programme succeeds in regularising the status passage. We highlight the ambiguity of the role of the health professionals in directing the status passage of the recently diagnosed. On one hand, health professionals empowered the participants by giving them access to professional knowledge and guidance and thereby supporting the status passage. On the other hand, the effort to direct responsibility back to the participants did not consider individual biographical situations, and thereby risked leaving the participants frustrated and unable to pass. Further, we point to the special significance of the socialising process between the participants, with the recently diagnosed being the novices asking questions and seeking guidance and the lay experts and the experienced participants taking the role of coaches, guiding the recently diagnosed managing the status passage into chronic illness.

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1. Introduction

It is well documented that chronic illness can be understood and analysed as a status passage in life (Glaser and Strauss, 1971; Tolhurst and Kingston, 2013). In formulating their formal theory of status passage in 1971, Glaser and Strauss suggested that individuals move from different statuses throughout the life course and used chronic illness as an example of such a life status. In constructing their theory, Glaser and Strauss used chronic illness as an on-going example of a substantive area within which the theory of status passage might be applied with success (Glaser and Strauss, 1971). They outlined how the major properties of status passages

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might provide a theoretical tool to describe and demonstrate how the health system and the individuals diagnosed with chronic illness negotiate, understand and try to control and direct the status passage. The six major interrelated properties of status passages are reversibility, temporality, shape, desirability, circumstantiality and multiple status passages. Recently, Tolhurst and Kingston critically evaluated status passage as a social theory that might enhance the research and understanding of the experience of dementia. They concluded that status passage provides valuable theoretical resources and encourages more theoretically guided empirical studies, enhancing the research on chronic illness (Tolhurst and Kingston, 2013).

The theory of status passage has been applied to various substantive areas. It has been utilised to understand the experiences of people diagnosed with Alzheimer's attending support groups (Beard and Fox, 2008); client-centred rehabilitation from the

perspective of people with long-term physical disabilities (Cott, 2004) how homosexual men living with HIV and AIDS experience status transitions as part of their HIV career (Lewis, 1999) and “what it means to fall in later life” (Kingston, 2000).

Since chronic illness is both an inevitable and irreversible status passage once one has been diagnosed, it is required that specific institutions and organisations are established to “manage, direct and control them” (Glaser and Strauss, 1971, p. 15). The principal institution set up to direct the passage into a chronic illness career is medicine with its corresponding organisation of the hospital, medical clinics and general practitioners (Glaser and Strauss, 1971, p. 15). Group-based patient education programmes are another organisational setup that has been developed as a complementary approach to traditional medical treatment (Taylor and Bury, 2007; Vassilev et al., 2011). These programmes have been established as both disease-specific and general approaches and have been developed at national, international and cross-national levels. The objective has been to delegate self-care and self-responsibility to people with chronic illness (Taylor and Bury, 2007; Vassilev et al., 2011) and to provide patients with tools to manage their chronic illness (Adolfsson et al., 2008; Ashe et al., 2005; Lorig and Holman, 2003; Mäkeläinen et al., 2009; Turner et al., 2002). The amount and use of group-based patient education programmes have expanded since the 1990s and are now a cornerstone in the politics of health promotion in most developed countries.

In Denmark, the political focus on the prevention and management of chronic illness has increased within the last 10–15 years. In 2007, the Danish public health system was restructured, and health promotion became the common responsibility of both regional (hospitals) and local health authorities. The government has financially supported the development of both disease-specific and generic patient education programmes at national, regional and local levels (Sundhedsstyrelsen Monitorering og Medicinsk Teknologivurdering, 2009).

In this article, we take the theory of status passage a step further and apply it to the empirical field of group-based patient education targeted at people living with rheumatoid arthritis. We argue that applying the theory of status passage (Glaser and Strauss, 1971) and central concepts from Strauss’s framework for studying identity change and development in adult life (Strauss, 2008) can enrich our understanding of ways in which participation might be significant to the everyday lives and the identities of the participants. We illustrate how, under certain circumstances, participation might turn out to be a status passage and a turning point in life for some recently diagnosed people joining the programme, while for others, it does not support their status passage into chronic illness. We demonstrate how central properties of status passage are at play and how they are shaped by the interactions among the different agents: participants, lay experts and health professionals in the social arena of a local patient education programme. The analysis builds on an ethnographic field study conducted in the context of a local Danish patient education programme aimed at people diagnosed with rheumatoid arthritis.

The rationale for applying the theory of status passage to the field of group-based patient education rests on the recognition of a close fit between the theoretical concepts and central properties of status passage and the rationale and aims behind the establishment and development of the substantive area, group-based patient education.

We understand group-based patient education as a health-promoting initiative, set up to regularise the status passage and help people to manage the status passage from being a normal person to becoming a person living with chronic illness and to support them in accepting and learning to live with this identity transition. The aim of the article is to critically analyse patient

education as a means to support the individual status passage into chronic illness, drawing on an empirical exploration of the inter-related dimensions of status passage at play during participation.

2. Theoretical perspective: status passage and turning point

The concept of status passage was developed by the anthropologist Arnold van Gennep at the beginning of the 19th century as he developed his theory of rites of passage. Van Gennep described how persons go through transitions across the life course, including those associated with birth, adolescence, old age, and death. Further, he suggested that movement between statuses is marked by rites of separation, transition or initiation (Van Gennep, 1960).

In developing their sociological theory of status passage, Glaser and Strauss adopted the definition of status passage as a theory, conceptualising personal development as a series of related transformations occurring throughout the individual life course and between different life stages or statuses (Glaser and Strauss, 1971). Strauss further described the concept as a framework for studying identity change and development taking place in adult life (Strauss, 2008, pp. 95–133) and illustrated how critical incidents act as turning points in life that force a person to recognise that she/he is not the same as before. The theory describes how individuals are socialised into having a new status and how these status passages are based on continuity and the forewarnings of others who have already passed into the same status and are able to describe what will happen and how it may be experienced. These interpretations of what will happen are described as embodying a special language of the group in which post facto explanations are at hand, such that individuals are offered ready-made definitions of new situations for which they have no definitions themselves. In addition, Strauss described the relationship between those who are going through the status passages and those who have already passed through as a coaching relationship in which the former need guidance and advice and the latter stand ready to guide and give advice (Strauss, 2008).

In this article, patient education is conceptualised as an institutionalised effort to regularise the status passage into the career of chronic illness. The career of chronic illness is defined as an unfolding or emerging process that develops over time and involves a process of adaptation that includes physiological, psychological, social and eventually economic changes (Corbin and Strauss, 1988). This process is not a linear and inescapable process, but rather a cyclic process with no firm endpoint. Career is conceptualised as a series of status passages that entail changes of the self (Glaser and Strauss, 1971).

Status passages are understood with reference to six principal properties: reversibility, temporality, shape, desirability, circumstantiality and the presence of multiple status passages (Glaser and Strauss, 1971). These properties will be elaborated in detail in the analysis.

3. Methods

The field study was performed between April and December 2012 and was part of a larger study on “everyday life and rheumatoid arthritis” that followed the development and implementation of a local Danish patient education programme on the significance of participation in both developing health services and patient education (Kristiansen et al., 2012a, 2012b, Kristiansen et al., 2015a, 2015b).

3.1. The setting

The programme was established as a collaboration between the

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