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# Safeguarding Self-Governance: A Grounded Theory of Older Patients' Pattern of Behavior in Relation to their Relatives in Fast-track Programs

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## Abstract

The aim of this study was to generate a grounded theory of older patients' pattern of behavior in relation to their relatives' involvement in fast-track programs during total joint replacement. Sixteen patients were recruited in orthopedic wards. Data collection included 11 interviews with patients and 15 non-participant observations of interactions between patients, relatives, and health professionals during scheduled meetings throughout the fast-track program. The constant comparative method was used for simultaneous data collection, data analysis, and coding. Safeguarding self-governance emerged in the analysis as the core category of our theory and pattern of behavior of the older patients in relation to their relatives. The older patients' main concern was to complete the fast-track program while maintaining autonomy, which they resolved through four strategies of actions: embracing, shielding, distancing, and masking.

**Keywords:** Fast-track program, grounded theory, older patients, relatives, total joint replacement.

## Introduction

Relatives often support their older family members through fast-track programs by sharing concerns, making decisions, and supporting with both emotional and practical issues (Berthelsen, Lindhardt, & Frederiksen, 2014). Although the support of relatives might increase the patients' abilities to recover, knowledge is needed about how older patients' actually relate to the involvement of relatives and how their pattern of behavior is displayed through social interactions with relatives.

Total hip or knee replacements are invasive surgical procedures performed in fast-track programs. Indications for replacements are often osteoarthritis accompanied by excessive pain and loss of mobility (Kehlet & Søballe, 2010). The orthopedic fast-track program begins with an initial pre-assessment visit at the outpatient facilities, and continues through admission to discharge 1-2 days after the surgery (Kehlet & Søballe, 2010). Fast-track surgery is defined as "the synergistic, beneficent effect on

convalescence achieved by adding multimodal evidence-based care principles and combining these with optimized logistics" (Husted, Solgaard, Hansen, Søballe, & Kehlet, 2010, p. 1), which means that the core areas of treatment and care—such as information, surgical stress reduction, pain management, mobilization, and nutrition— have been applied with systematic and evidence-based optimization (Kehlet & Søballe, 2010). Since the mean age of patients undergoing knee or hip replacement is 70 years for women and 68 years for men, consistent from 1995-2012 (The Danish Hip Alloplasty Register, 2013), patients have a higher risk of functional limitation, and are naturally more in need of practical support from relatives. During admission, care is supported by the core areas and administrated following clinical guidelines and the patients are required to participate actively and to adhere to standardized daily regimes. However, older patients might not have the strength and knowledge about this requirement, in which case the support of relatives may be decisive for the patients.

A measurable impact on quality, length of stay (Husted et al., 2010), and rehabilitation (Theiss, et al., 2011) was seen when relatives were involved before, during, and after total hip or knee replacement. A study consisting of 1722 observations in four American hospitals revealed a significant effect on the patients' outcomes regarding social support of the relatives before, during, and after total hip or knee replacement (Theiss et al., 2011). The length of stay was measurably shorter for patients with high or very high levels of relative involvement and the percentage of patients achieving the transfer-out-of-bed-goal was significantly higher for patients with a high level of social support (Theiss et al., 2011). Norlyk and Harder (2011) explored the recovery of 16 patients after elective fast-track colonic cancer surgery using a phenomenological approach; they found that patients felt more secure and ready for discharge when their relatives were involved. Their relatives took on a double role during the fast-track program. They occasionally acted as a support for the patient, pressuring him or her to comply with the program, and in other situations providing security and practical help during admission and after discharge (Norlyk & Harder, 2011). In a qualitative study, Wagner and Carlslund (2002) explored the perspectives of 17 women undergoing a fast track program for hysterectomies and found that relatives were attentive to the patients' situations and needs after the surgery and discharge thus protecting the women from physical strain (Wagner & Carlslund, 2002).

This study aimed to generate a grounded theory of older patients' pattern of behavior in relation to their relatives' involvement in fast-track programs during total hip or knee replacement. The research question that guided the study was as follows: What is the older patients' main concern and how do they resolve it?

#### Method

A classic grounded theory approach according to Glaser (1978, 1998) was used, aiming at generating a substantive theory abstract of "time, place, and people" (Glaser, 2009, p. 24). Through an inductive-deductive approach, theory was generated from patterns of behavior within a given substantive area (Glaser, 1998). The constant comparative method was the guiding principle for simultaneous data collection, data analysis, and coding (Glaser & Strauss, 1967).

Sixteen patients (nine women and seven men) participated in the study. Of the nine women, four were married and six were single (including five widows and one never married). Of the seven men, three were married and three were single (including two widowers and one never married). Their ages ranged from 70 and 94 years, and they all underwent total hip or knee replacement at one of the two participating orthopedic wards. All participants lived at home, independent of formal care; cohabitating relatives supported some participants. Eleven participants had relatives who were involved in the fast-track program. The relatives' ages ranged from 40 to 80 years and included spouses, children, foster children, friends, neighbors, nephews, and nieces. The remaining five participants refrained from having relatives involved during hospital admission.

## Data collection

Data collection took place from 2010 to 2011 in two Danish orthopedic hospital wards, specialized in fast track hip and knee replacement surgery. The first ward was chosen through initial sampling, being the place of employment of the first author as a full time PhD student. The second setting was selected through theoretical sampling due to assumed socio-economic differences between patients in the two settings.

Data consisted of 15 non-participant observations and 11 interviews. The observations focused on the social interactions between the first six patients, their relatives, and the health professionals during the scheduled meetings within the fast-track program before admission (the pre-assessment interview and rehabilitation seminar) and during admission (on the morning of surgery, the first round after surgery, and the discharge preparation meeting). Participants were recruited at the pre-assessment interview in the outpatient facilities, and observed throughout the meetings of the program. The observer (first author) sat at the back of the room during the meetings to reduce the impact of any ongoing interaction. The observer focused on the patients' behavior, verbal, non-verbal, and para-verbal communications. Field notes were taken during the observations.

One of the first six patients included was interviewed two weeks after discharge and after the observations. An additional ten patients were interviewed at the hospital. The first author conducted the interviews. An interview guide based on the emerging concepts was used during the first two interviews and was subsequently omitted to avoid preconceived ideas while focusing on any newly emergent concepts (Glaser, 2001). During the interviews at the hospital, the patients talked about how they usually received help from their relatives and what kind of support they expected to need after being discharged with a new hip. Eight interviews were tape-recorded and then transcribed verbatim. Field notes were obtained during the last two interviews in order to focus on data relating to the core category, (i.e., the predominant pattern of behavior) (Glaser, 1992). The interviews lasted between 9 and 61 minutes, decreasing in length at the end of the data collection process when concepts and categories moved towards saturation; the interviews became increasingly focused. Theoretical saturation was reached when further data did not elaborate the core category. The patients were recruited individually through theoretical sampling, where concepts generated through analysis and coding guided us in further inclusion of patients who could elaborate these concepts. Memos were written throughout the study as a brainstorming tool, to keep track of new ideas about the concepts and their theoretical relationship within the emerging theory (Glaser, 2011).

# <u>Data analysis</u>

Transcriptions from formal interviews, non-participant observations, field notes, and memos were initially analyzed through line-by-line coding, assessing each sentence while being open to the emerging concepts. After the initial coding, the software program NVIVO 9 was used to store data from the 22 codes that were generated. While coding and analyzing data, we looked for patterns in data and compared the codes and concepts with the new data. The authors participated in data analysis and comparison of concepts. Six categories were generated as we sought to identify a core category accounting for patients' latent pattern of behavior in resolving their main concern. These six categories were as follows: including, confiding, concerning, protecting, managing, and excluding.

When the core category and predominant behavior were identified as safeguarding self-governance—a precaution to guard one self and others and to protect autonomy—coding became more selective and aimed to delimit data collection to only those categories relevant to the core category. Theoretical sampling ceased when the core category was saturated and further data collection did not contribute with new knowledge to the emergent theory (Glaser, 1978). Theoretical codes of strategies emerged during the analysis and the six categories were modified into four strategies of action. These strategies, and the theory, are built around patients' pattern of behavior when resolving their main concern of succeeding in the fast-track program while maintaining autonomy in relation to the involvement of relatives. Eventually, memos were sorted and written according to the classic grounded theory approach (Glaser, 1998). During theoretical coding, it became apparent how the patients' strategies of actions were connected to their gender and marital status.

# Ethical considerations

The study was approved by the Danish Data Protection Agency (j.nr. 2010-41-4462). The National Committee on Health Research Ethics was presented with the project description and found formal evaluation to be unnecessary. The participating patients, relatives, and health professionals were informed that participation was voluntary, and that withdrawal from the study could take place at any time, without consequence for treatment or care. Data collection was performed after written consent was obtained from the participants.

# The Theory of Safeguarding Self-Governance

Safeguarding self-governance emerged as the core category of our theory and conceptualized the pattern of behavior of older patients in relation to their relatives in their fast-track programs. The older patients' main concern was to complete the fast-track program while maintaining autonomy, which they resolved through four strategies

of actions: embracing, shielding, distancing, and masking. The strategies described the patients' actions of maintaining autonomy by deciding which relatives were allowed to be present, when their presence was desired, and what kind of support was acceptable so the patients could stay in charge of their fast-track program. The strategies of actions, chosen by the patients, appeared to be related to their gender and marital status (Table 1). The strategies share some similarities with each other because social strategies are commonly used and a part of the patients' overall pattern of behavior.

	Married	Single
Women	Embracing	Shielding
	Needing relatives involvement Including relatives based on an	Partly needing relatives involvement
	essential need for their presence during admission and after discharge	Including relatives for visits during admission
	-	Excluding relatives after discharge
	Accepting dependency	to protect relatives from being burdened
		Refusing dependency
Men	Masking	Distancing
	Partly needing relatives involvement	Not needing relatives involvement
		Excluding relatives to protect
	Excluding relatives during	themselves from relatives during
	admission to protect themselves from relatives	admission and after discharge
	Including relatives for practical support after discharge	Refusing dependency
	Accepting dependency	

Table 1: The patients' four strategies of actions and their apparent relation to gender and marital status.

# Embracing

The strategy of embracing was preferred by married women and explained how they involved their husbands, based on an essential need for their support and presence during the fast-track program. The married women did not perceive their autonomy as being threatened by their husbands' involvement; rather, it was supported and retained, and the married women accepted being dependent on their husbands to complete the fast-track program. This dependency is illustrated in the non-participant observation field notes, where two of the married female patients' husbands were present at every scheduled meeting—something that did not occur with the other participants. These married female patients were autonomous together with their spouses and were comforted by the closeness of their husbands during admission and after discharge. The feeling of having their loved ones close by when the married women needed them comforted the women; they considered closeness to be their husbands' most important attribute. Their need to share the experience with their husbands was vital and the women needed their husbands' presence as well as their emotional and practical support. Embracing their relatives' involvement was a natural thing, which differs from the strategies of shielding, masking, and distancing, where the relatives' involvement was disregarded. Through embracing, the married patients confided in their husbands and relied on their support for decision-making.

The decision about surgery was an important one for the married women and they often involved their husband in the decision-making process. The decision-making process differs from distancing, where the single men excluded their relatives, and made the decisions by themselves, and from shielding, where the single women refrained from including their relatives for fear of burdening them.

## <u>Shielding</u>

The shielding strategy was preferred by single women with children or nieces and nephews as the potential supporters. The single women completed the fast-track program and maintained autonomy by avoiding help from their relatives. Through shielding, the single women protected their relatives from being burdened; these women were concerned about the well-being of their relatives their low financial capacity, decreased health, and heavy workload in spite of the fact that these single women needed their practical and emotional support. Field notes from the observation of a pre-assessment interview illustrated a single female patient's need for her daughter's assistance: "The nurse asked the patient which pain medication she was currently using. Confused, the patient looked to her daughter for the answer. The daughter replied that her mother took eight paracetamol tablets per day". The single woman concealed her anxiety and ensured her relatives that she was capable of self-management.

Avoiding being a burden to relatives was a prominent aspect of shielding. Practical support was occasionally refused by the single women, but later accepted if the relatives were insistent. The appreciation of the willingness of relatives to support and act as a safety net for the patients was balanced by the patients' need for autonomy. Such need related to the strategy of masking where support was not accepted until after discharge. Relatives were protected by the single women who accepted home care and admission to a rehabilitation facility to limit the amount of help from relatives. This aspect differs from distancing, where the single men perceived relatives as superfluous and excluded them in order to protect themselves.

## **Distancing**

The strategy of distancing was preferred by single men and explained how they dissociated relatives from the fast-track program, during admission and after discharge. The strategy was seemingly used to protect themselves from the opinions and interference of their relatives. Distancing also explain how single men wanted to be in charge and manage without interference. The single men completed the fast-track program while maintaining autonomy guided by a high sense of self-governance.

The single men managed daily life alone with faith in their own abilities and took care of themselves, even though, in one case, it meant having to crawl up the stairs to visit the bathroom. Although practical support was needed, these men discarded dependency and excluded relatives as superfluous in order to maintain autonomy without relatives. The single men also attended the scheduled meetings alone, only informing their relatives when they considered it necessary. Such behaviors differed from those of married women in the strategy of embracing, where the husbands' involvement during the scheduled meetings was considered important. Taking pride in independence and making their own decisions—such as doing housework, in spite of patients' decreased functional abilities—was prominent in the strategy of distancing. The relatives' presence was considered a redundancy for mastering the fast-track program, and visits were declined by single men because of their desire to succeed alone and make their own decisions. Married men also declined visits during admission through the strategy of masking, but accepted being dependent of their wives after discharge.

#### <u>Masking</u>

The strategy of masking was preferred by married men and explained their need to complete the fast-track program while maintaining autonomy alone to protect themselves from their relatives' interference and worry; but they did, however, depend on the support of their wives after discharge. To display their autonomy, these married men maintained a masculine façade of self-governance during admission towards their wives and the health professionals.

The married men regarded total joint replacement as an easy procedure, that it was a matter of getting a bone repair and not a legitimate cause for involving relatives who were subsequently excluded during admission. These men met the worries of relatives with surprise, as they did not regard the surgery as an illness. Previous hospital experiences had left the impression that relatives were interfering and curious, which was also the case for the single men using the strategy of distancing; however, distancing differs from masking by also excluding relatives after discharge. Keeping up a façade was considered necessary by married men going through total joint replacement to maintain the image of staying strong for their worrying wives. Accepting help was apparently not in conflict with the masculine façade for the married men as they regarded and received their wives' support after discharge as a natural thing.

Even though the married men excluded their wives during admission, they accepted dependency after discharge when their wives' practical support was needed; such behavior also, relates to the married women and their strategy of embracing.

## Discussion

The theory of safeguarding self-governance demonstrated how older patients tried to resolve their main concern of completing the fast-track program while maintaining autonomy through the four strategies of action of embracing, shielding, distancing, and masking.

Autonomy was a prominent aspect in our theory where the patients' actions to maintain autonomy resembled the concept of autonomy viewed by Gillon (1995), a philosopher in medical ethics, who regarded independence as a vital component in the concept of autonomy. Gillon (1995) described how the capacity to think, decide, and act on the basis of such thought and decision freely and independently and without hindrance is an essential factor. This type of autonomy is explained through the single patients' strategies of distancing and shielding, where they felt independent without the support of relatives. In a review study of self-determination theory and autonomysupportive behavior, Deci and Ryan (2012) did not define autonomy as similar to independence. Instead they distinguished between being autonomously independent, where patients chose not to depend on others, and autonomously dependent, where they chose to do so, without being controlled. In safeguarding self-governance, older patients' autonomy did not presuppose independence, at least when it concerned married patients who accepted dependency of relatives through the strategies of embracing and masking, without feeling less autonomous. The aspect of accepted dependency as a part of autonomy has also been addressed by La Guardia Ryan, Couchman, and Deci (2000) in their intervention study of family members. Here, autonomy was not always perceived consistent with individuals, but described as how one person could be dependent of support, and willingly rely on the care of others while still feeling autonomous (La Guardia et al., 2000).

An association between the patients' gender and autonomy was found in our study. Women seemed more likely to involve their relatives than men, who insisted on managing independently and even seemed to protect themselves from their relatives' opinions. In a Dutch study of autonomy-connectedness and gender, Bekker and van Assen (2008) examined a sample of 2256 people and found that women were more sensitive to others, while men had higher scores of self-awareness. Moreover, the women in our study seemed to accept dependency on relatives as part of being autonomous, maybe even a prerequisite for autonomy, which was seen in embracing and shielding. This aspect was also seen in Deci and Ryans' study (2012) about the selfdetermination theory, where they showed how dependence could be a precondition for autonomy if one relies on others for guidance. In the safeguarding self-governance theory, men were more reluctant to accept dependency and used the strategies of masking and distancing and insisted on managing the fast-track program by themselves. Deci and Ryan (2012) defined this aspect as autonomously independent, where people choose not to be dependent on others for fear of being controlled or pressured into depending on the others' leadership.

Such was not the case for the married patients in our theory where autonomy was maintained by the support of spouses. Married women accepted dependency on their husbands during and after the fast-track program through embracing; such behavior did not interfere with their feelings of being autonomous. Neither did the married men who included relatives after discharge for practical support, which was in concordance with the findings of Van Nes, Runge, and Jonsson (2009) in their exploratory case study of the everyday life experiences of older couple after suffering from a stroke. They found that the couples acted as one entity, conceptualized through "one body, three hands, and two minds", (Van Nes, Runge, & Jonsson, 2009, p. 198) and showed how they managed daily living together by assisting each other.

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In our study, the behaviors of single patients differed from that of the married patients. Through the strategies of shielding and distancing, single patients seemed to rely on their own abilities for completing the fast-track program, while maintaining autonomy without their relatives' involvement. Single men used the strategy of distancing to dissociate from their relatives during admission as well as after discharge, to minimize the impact of opinions and interference of others. The occasional undue pressure of patients' families was described in an essay by Ho (2008) about family involvement in medical decision-making. Ho (2008) stated that the patients' concern of being influenced by paternalistic pressure from family members is important in western bioethics because patients are often in different power positions than those people surrounding them. At the same time, Ho (2008) rejected the image of patients as passive care recipients and explained how the patients' dignity and autonomy must be preserved.

Single women in our theory were seen to have the same needs as men: to complete the fast-track program while maintaining autonomy without their relatives' involvement. However, they used the strategy of shielding to protect relatives from being burdened, and as a way to maintain their autonomy without the presence of relatives, even though practical and emotional support was needed. In a study by Cahill, Lewis, Barg, and Bogner (2009), 50 semi-structured interviews of patients over the age of 65 were conducted; older patients' discussed the concept of burden, which was related to not wanting to complicate the busy lives of their adult children. The patients felt guilty about having health problems and concerned that their children were overly worried about taking care of them. Through shielding, patients excluded relatives from support during admission as a consideration for their well-being and concern for their busy daily lives. However, the single women in this study occasionally appreciated their relatives as a safety net after discharge. A descriptive study of 35 patients going through total hip or knee replacement, showed similar results with patients expressing concerns about the consequences of early discharge for them or their relatives, particularly managing pain and mobility problems (Hunt et al., 2009).

Our theory of safeguarding self-governance indicated that autonomy is important for the patients' involvement of relatives in their fast-track program during total hip or knee replacement, and showed that men and women have different strategies for achieving this associated to their marital status.

# Study limitations

Our theory is based on a small sample consisting of sixteen patients. However, according to classic grounded theory, theoretical saturation is not perceived through the number of participants but through the concepts and categories relevance for the emergent theory and core category (Glaser & Strauss, 1967; Glaser, 1998). Through theoretical coding we found how the patients' tried to resolve their main concern using four strategies, which were related to the patients' gender and marital status. Even though it could be argued that our sample was too small for a generalization in this size, nonetheless, we found gender and marital status to be important for the four strategies of patients included in the current setting at the specific time. The employment of the first author in the ward that was initially chosen for data collection could also be of scrutiny. Glaser (1998) emphasized the importance of the researcher studying an area he or she knows nothing or little about and let theoretical sensitivity guide him or her. The first author was familiar with the area of interest, but was also interested in finding out *what was going on* with the older patients and their relationship to relatives as they were discharged three days after invasive surgery. Glaser (1998) stated that if you study an area you know about, you are going to have more variables, and you have to suspend that knowledge: "much like a judge tells a jury to disregard something they have heard that is not to be considered in reaching a verdict" (p. 120).

# Implications for practice

This theory illuminates older patients' capacity to complete the fast-track treatment program while maintaining autonomy. Autonomy was revealed to be a central issue for older patients undergoing elective surgery, but also that it was possible to achieve autonomy while being dependent.

This new knowledge implicates nursing care for older patients with the needs of patients to balance autonomy and dependency in relation to the formal and informal care they received. Older patients' display of heterogeneous patterns of behavior to maintain autonomy when involving relatives emphasizes the need for health care professionals to apply an individualized approach to the involvement of relatives.

# Theory quality

The quality of the emerging theory of safeguarding self-governance was evaluated by: fit, work, relevance, and modifiability (Glaser, 1978). The theory already meets the criteria of fit, by consisting of data collected from the substantive area of orthopedic hospital wards where total joint replacements were performed, and work, by explaining older patients' actions in the area examined. The four strategies of the theory and the relation to gender and marital status were found relevant by health professionals when presented at the two orthopedic wards where the study was conducted and in national events and conferences. Further research is needed to establish the theory's relevance to older patients' in fast-track programs during total joint replacement. The theory should also be modified by new data, exploring new tendencies in the theory and to further modify the relation to gender and marital status.

## Conclusion

The safeguarding self-governance theory showed how older patients completed their fast-track program while maintaining autonomy through four strategies of embracing, shielding, distancing, and masking. In our theory of safeguarding self-governance, the patients' autonomy did not presuppose independence as dependency of relatives could be accepted without feeling less autonomous. However, this aspect was related to the gender differences and marital status of the patients, as women would more willingly accept their relatives' support and men excluded the relatives' help in order to feel

autonomous. We also discovered that the level of the relatives' involvement was limited to the extent decided by the patients, who chose who was to be involved, when they were involved, and with what kind of support.

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# **Authors' contributions**

The paper is a part of a PhD study conducted by first author and supported by second and third authors as academic supervisors.

The detailed authorship contributions are as follows: The first author contributed to conception and design of the study. She initiated contact with the hospital wards including participants, collected, analyzed, and interpreted data. She drafted the paper and was a part of the final approval of the version to be published. The second author was a supervisor and contributed to conception and design of the study. She participated in analyzing and interpreting the data, and in drafting and revising the paper; she was a part of the final approval of the version to be published. The third author developed project idea and concept, obtained the funding, participated in data and analysis, supervised, and critically reviewed the protocol and manuscript.

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