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Patient Autonomy, Decision-making and Cultural Impact in Elder Care in Albania

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Abstract

BACKGROUND: Maintaining patients' autonomy and including them in the decision-making process is crucial in eldercare. This study explores the cultural impact of independence in Albanian nursing homes. This paper follows previous publications from the same project.

AIM: Based on the previous research on ethical and legal issues, the aim was to identify how and why autonomy is frequently compromised.

METHODS: An exploratory qualitative study with semi-structured interviews and field notes was conducted. The field notes and interviews were analyzed using inductive category formation following a qualitative content analysis approach to identify potential causes and core themes. For this study, 15 nurses from three public nursing homes, two private nursing homes, one palliative care center, and one daily care center in Albania were included in the study. The observations and interviews were conducted between June and August 2018 in 7 eldercare institutions.

RESULTS: The study shows that autonomy is frequently compromised in this setting. Although residents have some freedom concerning movement, nutrition, and hygiene, they are mainly excluded from the decision-making process in treatment or palliative care. Patients are purposely misinformed about their diagnosis so that they live life "normally until the last day." Here, a robust cultural aversion to talking about death comes together with a firm reliance on the family's decision-making.

CONCLUSION: The study indicates that strengthening patients' rights by improving nurses' education can lead to more severe family conflicts. Expanding patient rights can be perceived as limiting the rights of the family. This demonstrates the difficulty of imposing "western" health regulations in different cultural contexts. In addition to legal and ethical education, preparing nurses for conflicts with the residents' families and creating awareness for fundamental patient rights among their relatives are critical steps to improve patients' autonomy in Albania.

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Introduction

Autonomy is an essential principle in nursing. To make decisions about one's treatment in daily life is an integral part of most legal and ethical regulations and, above all, a fundamental human right [1]. However, autonomy is a principle that is compromised in the daily care of the elderly. When patients refuse treatment or nutrition or enter a mental state where decisions must be made on their behalf, autonomy cannot be upheld ultimately. The principle of "informed consent" is one of the cornerstones of patients' rights and plays a crucial role in a modern understanding of nursing and care [2], [3].

As an extensive literature review showed, patients' involvement in decision-making and trying to respect their will at the end of life in advanced directives is a crucial dilemma for healthcare workers, as evident in many studies [4], [5]. At the same time, legal regulations prevent abuse, ensure beneficence and fairness, and maintain a high level of autonomy for the elderly to exert their fundamental human rights [6].

However, when researching ethical and legal issues in elder care using semi-structured interviews, cases of restricting autonomy were frequently reported. This secondary result led to a more detailed analysis of the emerging subject. Throughout the observations and the interviews, nurses raised the issue that patients were kept misinformed about their diagnosis at their family's wish. This stands in strong contrast with values and laws in the EU member states, for example, the European Charter of Patients' Rights (European Commission, 2002). Many cultures do not prioritize individual autonomy, limiting the patient's decisionmaking ability and giving preference to the family or healthcare professionals' choices for their health and well-being [7]. In a study by Scott et al., patients and nurses in Scottish nursing homes were interviewed regarding decision-making and informed consent. Fiftyfour percent of nurses felt that patients were informed about what they undergo during treatment, while only

15% thought they were not told [1]. It is noted in the study by Scott *et al.* that some interviewed patients had cognitive difficulties, and according to the nurses' insights, patients often did not want the information. However, the overarching conclusion was that autonomy by patients was desired in some decisions. The consent agreement differed widely between nurses and patients, and it was noted that informing patients is not the same as "informed consent" [1]. Furthermore, there is a lack of literature related to autonomy and decision-making issues in eldercare in Albania.

Therefore this study aimed to explore restricting patients' autonomy in Albanian eldercare institutions. In this study, we investigated the following questions:

- How and why is patient autonomy compromised in Albanian nursing homes?
- What factors influence the current practice of misinforming patients about their diagnosis?
- What steps can be taken to improve the enforcement of patient rights in Albania?

Data and Method

An explorative qualitative research design was selected for the study. Data were collected through semi-structured interviews and field notes [8]. These interviews focus on considering the participants in their working environment and considering the researcher's observations. Field notes were taken during the visits to the care institutions and contrasted with the interviewed statements. These records focused on the conditions inside the institution, and they regarded the well-being of the residents and noted staff-resident interactions.

A qualitative content analytical approach was followed for analyzing the data [9]. The flexibility of Mayring's methodology allowed a follow-up on exciting insights that were not initially intended in the interview study. Here, shifting the direction of the analysis from the cognitive background of the communicator to their motivational and socio-cultural environment allowed further insights (Figure 1) [9].

As this study requires both: Cultural familiarity and specific language skills, the observations and interviews were led by the first author (N.P.) and second author (Z.SH.), who are not only experienced nurses and doctors, teachers, and researchers but also are closely familiar with the Albanian culture and language. The interviews were analyzed by the first author (N.P.) and third author (A.M.), an external research consultant.

Sampling and data collection

Purposeful sampling was used to recruit participants for the study. The participants are nurses who work at eldercare institutions [10]. For establishing

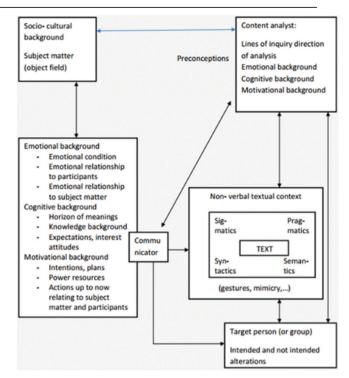


Figure 1: Content-analytical communication model (Mayring 2014, p. 49)

initial contact, the directors of different institutions were contacted via email. After getting permission for the observation within the institutions (seven eldercare institutions) and the interviews, the contact information was shared, and the nurses were contacted. Of 30 initial contacts, 15 nurses were willing to participate in the study and followed through until its completion [8]. Interested nurses received a consent form through mail or email and received verbal information about the project. Informed consent was ensured before conducting the interviews. Feedback from the nurses was included, and additional questions were answered. All nurses participated entirely voluntarily and were free to interrupt or leave the study at any time without negative consequences.

A face-to-face semi-structured interview was chosen to allow the participants to respond as freely as possible [11]. Interviews were conducted in the Albanian language and were carried out by native speakers who work in the same profession. A digital audio recording of the interviews was created with the interviewees' consent to enable detailed analysis. These audio data were transcribed and translated into English by the first author (N. P.) and a professional translator to study the research team and access this data for a wider audience [12]. The transcripts were connected to the primary audio data in the research software (MAXQDA 2020) so that in any case of uncertainty, the team could refer to the original records. Alongside the 15-60-min interviews, biographical data such as age, gender, years of experience, formal education, and type of institution were collected through a questionnaire that participants fulfilled after finishing the interviews.

Ethical considerations

This study followed the principles of the Helsinki Declaration [13]. Furthermore, approval was given by the Research Committee for Scientific and Ethical Questions (RCSEQ) of the Private University for Health Sciences, Medical Informatics and Technology (UMIT) in Hall in Tyrol, Austria (RCSEQ, No. 2117). All researchers were aware of the importance of the protection of human subjects. Informed consent of the study participants was obtained in written form. Once the data were collected, the participants were anonymized using identifiers (IN01-IN15), and their names were removed from the transcribed data. The principal author (N. P.) kept the primary audio data in a secured file. The rest of the team worked with the anonymized English transcripts. During the entire study, the participants were free to withdraw at any time without any negative consequences. The interviews were confidential and were not shared with the institutions' heads or co-workers. The interviewees could request the deletion of their data at any time.

Data analysis

As a methodological basis for the analysis of the transcripts, qualitative content analysis following the model of Philipp Mayring (2014) was used (Figure 2).

The model above shows the adaptation of Mayrings content analytical model with the specific steps in brackets. An analytical technique of inductive category formation was chosen to structure the material and summarize the findings. Mayring's eight stages of inductive category formation [9] were followed (Figure 3).

Following the feedback cycles of coding and reworking the category system, the material was worked through three times in total. The researchers updated the category system after the first and second iterations and were frequently discussed by the team. The inductive categories that matched the selection criteria were thus turned into main categories.

As patients' autonomy became evident as an issue of importance across many of the categories, analytical sets were created to deepen the analysis. Beyond Mayring, further method literature on qualitative analysis was consulted and incorporated into the research design to establish a multifaced view of this method [14], [15], [16]. The method was implemented with the qualitative data analysis software MAXQDA2020 [17]. The quality criteria of the content analysis of Philipp Mayring were taken as guidance for ensuring methodological rigor [9]. By working through the material 3 times and using an intercoder reliability test after the second, reliability was tested to ensure stability and construct validity. For inter-coder agreement, the final coding of the data was carried out by the first author (N. P.) and the second author (A.M.) independently. Any issues were resolved by

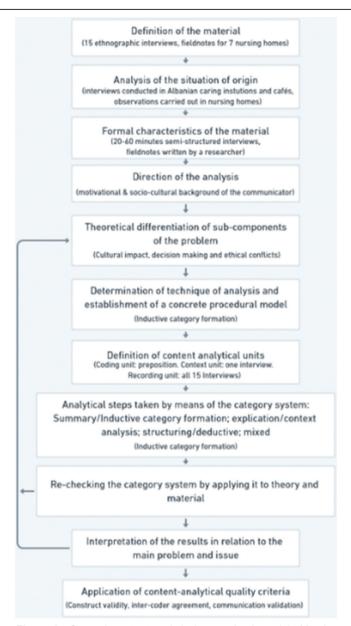


Figure 2: General content-analytical procedural model, Mayring (2014), p. 54

personal discussion and validation within the research team. Furthermore, the professional experience of the first and second authors as nurses and their cultural familiarity with the research participants improved the validity of the research method and results [8].

Results

For this study, 15 Albanian nurses were interviewed. These nurses can be differentiated into two groups based on their age/experience and education. Ten nurses hold a university diploma and have only a few years of professional experience. Five nurses only have a college education but several decades of experience. Further socio-demographic data are shown in Table 1.

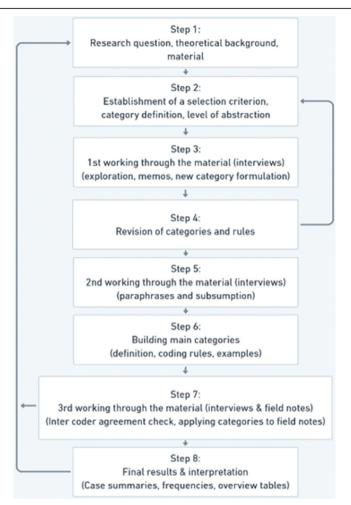


Figure 3: This analysis's concrete procedural model based on Mayring (2014) p. 80

Three main categories were identified to hold fundamental importance to autonomy within the interviews. These categories and their main components are given below (Table 2).

Table 1: Socio-demographic data

Variable	Number of participants	Number of participants
variable		
	College	University
Gender		
Female	4	5
Male	1	5
Age		
21–30	0	3
31-40	0	5
41–50	2	1
51–60	3	1
Experience (years)		
0–1	0	3
2–5	0	2
6–10	0	4
11–20	1	1
20+	4	0
Institution	No. of participants	No. of participants
Public Nursing home (3)	5	2
Private nursing home (2)	0	4
Palliative care center (1)	0	2
Daily elderly care center (1)	0	2

Cultural impact and religion

The interviewees' statements about their own culture were analyzed to identify the cultural impact on ethical and legal issues, such as patient autonomy.

Table 2: Categories and components

Category	Components
Cultural Impact	 Religion's role is limited to the choice of last rights. Here, patients' wish is respected
	Albanians portray themselves as very communicative, both
	positively (listening and emotional support) and negatively (lack of confidentiality)
	The custom not to talk about death and not to tell patients their diagnosis is attributed to the Albanian culture and is highly
	problematic for autonomy in palliative care
Decision Making	In decision-making about the treatment, the patient's autonomy is
	rarely considered. The doctor legally makes all decisions, but nurses
	display a strong level of independence. Patients have little choice but
	to accept the medication
	In palliative care, the medical staff is seen as the advisor of the
	patient's family. The family decides on the patient's behalf regardless of their will or state of consciousness
	 Patients' expression of a will to die is not taken seriously by staff or family members
	Patients' autonomy is valid regarding their nutrition, freedom of
	movement, and hygiene
Ethical Conflicts	
	Violent physical conflicts are prominent in mixed institutions (geriatric care and mentally ill)
	Older nurses with a minor education level frequently experience conflicts with residents, whereas younger nurses with a university education frequently experience conflicts with the family

Instead of prompting them to speak about specific implications of their culture, their language usages of "we," "our culture," and "Albania" served as a basis to recreate their subjective theories about their own culture and its impact on their daily lives.

Only about half of the interviews explicitly addressed the impact of religion or Albanian culture, and only religious beliefs could be observed in one institution. Older nurses are less inclined to attribute behavior to their culture. In particular, the younger nurses reflect on their practices from a cultural perspective. They often have gathered experience abroad or have encountered other customs during their education.

Here, a significant factor is the impact of Albania's specific political, economic, and historical setting. A lack of legal regulations is frequently reported, partially corrected by legislation in the recent past. Regulations concerning isolation and euthanasia are known to exist but are often not fully understood by the nurses. Furthermore, during the observations, the lack of resources was visible and can be attributed due to the limited power of the Albanian economy. Mainly the public nursing homes are often located in old buildings with insufficient equipment:

"This center is the typical model of state asylums in Albania. These centers were built during the communist era, around the 60s and the 70s, and there have been very few reconstructions since then" (Public Nursing home 01, Postulate. 5).

The limited resources of Albania are in part compensated by tolerating people who are not able to pay and providing hospital services free. The situation in many caring homes is made more difficult as older adults are kept together in public nursing homes with young mentally ill patients and, in some cases, even ex-prisoners:

"My colleague ZSH and I are near the 'Psychiatric Supported Homes' center, a rehabilitation center where people of different ages live. Still, most of them are elderly with various problems such as Alzheimer's. [...] We go out from the office and climb the stairs to the next floor, where there are five double rooms for women, five double rooms for men (all the rooms have balconies), and two large bathrooms." (There are three other similar houses in the same yard). Eighty people live in all four places, of which 45 are elderly (Public Nursing home 02, Postulate. 2–5).

This mix of residents leads to dangerous conflicts between patients and between patients and staff.

The older nurses mainly reflect on the political history of Albania. Elements of the recent past under the communist regime of Enver Hoxha (1945–1985) are still eminent. Senior staff was influenced in their career choice and made frequent comparisons to the communist period/past.

"I can say that we have been more protected during communism. Things were arranged differently, better during communism. When democracy came into power, unskilled people started finding jobs due to their connections. Then, the Ministry of Health oversaw the institution, whereas now, the Ministry of Labor and Social Affairs is in order. Then, the institution was available for only the elders who suffered from different illnesses, whereas now, the center is like a psychiatric institution. Sometimes, we become nervous with the elders. Some employees try to hit the elders" (Interview12, Postulate. 28–31).

Furthermore, the lack of statements about religion and an unwillingness to talk about it is likely connected to the solid atheistic policy of the communist regime. Only in one case, religious belief could be observed in one of the palliative care centers:

I asked her why she keeps that photo, and she answered me: 'I believe in God, and I think that the saints and my prayers are going to ease my sufferings and my death..." (Palliative care center 01, Postulat. 9).

Many interviewed do not seem to take religion seriously or ascribe its importance aside from last rites and calming the terminally ill. Overall, religion does not play a significant role in the nurses' ethical considerations. Religion is mainly mentioned as a means of palliative care and for the requirement of last rites. Although some patients are religious (Muslims and Christians) and some caring institutions have a religious background, tradition and family strongly seem to outweigh the impact of religion.

Despite this, the nurses take the wishes of last rites and burial places seriously. They show a strong

inclination to follow the wishes of the elderly. Here, autonomy is granted to the patients.

Not telling the truth to patients about their condition comes up frequently in the interviews as something unique in Albanian. Let them usually live until the last day is the philosophy. Although such truth-telling issues were observed during the visits to the institutions, the connection to Albanian culture was made by the nurses in the interviews, and it did not play an explicit role in their daily care. The families require medical staff not to tell the patient their state and outlook. Violation of this wish can result in conflicts with the family. The younger team with university education is thus in a difficult situation of knowing the legal requirement and still following the family's wish. The mindset here is well described in the following two quotations:

"We only inform the family members about the resident's diagnosis. We never tell the patient his diagnosis. It's not good to tell the patient his diagnosis when he is not in good condition because he might become agitated. The best thing to do is not tell him his diagnosis because he usually continues life until the last moment" (Interview 07, Postulat. 36–39).

The same behavior could be observed in the

field:

"My colleague ZSH and I observed in this caring center, and what caught our eye: Every decision regarding therapy or anything else is not taken by the patient himself but by their families. Patients are denied their right to receive accurate information regarding the diagnosis, the treatment, etc. They are denied the right to decision-making" (Palliative care center01, Postulate. 18–19).

An interesting conversation with a patient from a palliative care center provided additional insights from the patient's perspective:

After we greet Emin, he starts talking to the nurse he has known for a long time. Emini has been a professor at the university and says: - "I have been suffering from skin problems for a year. At first, I thought it would be just a skin infection, but over time I get a lot of sores on my skin which is not closing. The children told me to be calm as I would recover quickly, but I read a lot and realized that I suffer from skin cancer. Anyway, I kept it a secret to myself, and I pretended not to know anything." (Palliative care center 02, Postulate. 7).

It becomes evident that the mentally healthy and more educated elderlies also maintain the illusion of not knowing their diagnosis. This is a broader phenomenon that puts patients as the "victims" who are misinformed and shows how they play an active role in maintaining this condition. This extends even to young

terminally ill patients. The staff tries to solve this conflict of interest by signaling the patient their diagnosis nonverbally or telling the family to inform them.

Decision-making

By being in such a disadvantaged position and being intentionally misinformed, the level of autonomy of the patient in decision-making is minimal. On entering the institution, they are not able to make decisions autonomously. The consent of the family is always required to allow admission to the institution, whereas the opinion of the residents themselves is not always taken into consideration:

"We try to provide them with information. For instance, a female elder who came yesterday to register told me that she had a daughter. I asked her whether her daughter knew that she wanted to go to the house of the elderly. She said no. Then, I told her to go and ask her daughter if she agreed to bring her here. I would not register her without her daughter's permission" (Interview 12, Postulate. 35).

When it comes to the daily decision-making about treatment and medication, the doctor is recognized as the legal decision-maker. However, throughout the interviews, nurses show a strong level of autonomy in providing the prescribed treatment and deciding about it themselves. Here too, the patients have a minimal influence on the decision, and they are forced to accept the treatment one way or another, and sometimes/partly, medication is evenly mixed into their food:

"Sometimes, they refuse treatment. However, we try to explain that it is the best for them. They agree because they have no other option. In some way, they give up and accept the treatment" (Interview 11, Postulate. 111).

In the observations, conflicts about the decision-making process in palliative care appeared predominantly in the daily care centers. When it comes to decision-making in palliative care, the family takes over the role of the core decision-maker. As the patients are not informed about their diagnosis, the decision is referred to their relatives regardless of their mental state or will. Here nurses and doctors often act as advisors to the families. The elderlies themselves are not a part of this decision-making process, and their opinions are rarely heard or even followed. Depending on the availability and level of interest of the family, the decision can rest with the medical professionals, yet it becomes clear that the family remains the deciding authority:

"The doctor decides for the therapy, of course. Yet, if the families disagree, the doctor can't apply it against their wishes" (Interview 08, Postulate. 33).

Although the autonomy of the elderly is strongly limited in their medication and at the end of life, their level of independence is much better about their daily needs. Respect for the elderly and the nurses' duty are upheld as important concepts. Therefore, in everyday decisions such as nutrition, freedom of movement, and hygiene, much more emphasis is on accepting the patient's will. If they are mentally able, the residents are allowed to go out on their own, some of them cook for themselves, and bathing times may sometimes be shifted to accommodate their wishes. Although the resources of the caring institutions show considerable limitations, the interviewees seem to recognize the residents' desire to decide on such issues as legitimate.

Ethical conflicts

Quantitatively analyzing the daily conflicts between staff, residents, and family, a distinctive difference arises between younger nurses with higher education and older nurses with only a college education (Table 3).

Table 3: Conflicts and level of education

Code	College	University diploma
Forms of conflict		
Physical violence	10.8%	10.9%
Legal conflicts	7.5%	9.8%
Verbal violence	11.8%	2.2%
Gender and sexuality conflicts	2.2%	8.7%
Ethnic, regional, or class conflict	0.0%	3.3%
Conflict groups		
Resident-staff	34.4%	17.4%
Family-staff	6.5%	20.7%
Resident-resident	10.8%	9.8%
Staff-staff	10.8%	7.6%
Family-resident	5.4%	7.6%
Family-family	0.0%	2.2%
SUM	100.00	100.00
N = Documents	5	10

Physical and verbal violence between residents and staff is reported most frequently. However, when considering the nurses' level of education, it becomes clear that younger and more educated nurses reported distinctively less verbal violence.

It indicates that older and more experienced nurses try to avoid conflicts with the families and follow their wishes. Instead, their disputes focus on the patients themselves. In contrast, the younger nurses with university degrees are more likely to know about current legal and ethical requirements, such as telling the patient their diagnosis and empowering them to make decisions themselves. With this behavior, they tend to conflict with families expected to decide and act on the patients' behalf by tradition - raising the crucial questions of how young nurses with proper legal and ethical education can be prepared for conflicts with the family.

Beyond this, other conflict types are rare. Formal legal conflicts are hardly ever given, and all the statements counted above record a lack of legal disputes. Confrontation, instead, takes the form of insult or threat than the legal form. A few notable exceptions

are legal cases about legal representation. Even cases of murder committed by patients or suspicions of neglect are only exceptionally rarely executed legally.

Gender and sexuality conflicts are likewise rarely made explicit. However, the Albanian culture is described as very patriarchal by the interviewees. For example, in some homes, female elderly is required to help with everyday work, whereas men are not. Furthermore, sexual violence can occur, especially in mental institutions, and when a lack of staff leads to a loss of control over the patients.

Discussion and Conclusion

Violation of the principle of autonomy comes up as a recurring theme throughout the observations and the interviews.

Cultural impact and religion

The patients' autonomy is severely limited and often not recognized as legitimate by their families, especially when decision-making regarding treatment or palliative care. They reflected the cultural impact of a strong reluctance to talk about death and the socioeconomic power of the Albanian family over their family members. This reluctance to discuss patients' conditions is not a concept exclusive to Albania. In a UK study, were some nurses avoided discussing patients' condition (and nearness to death) with them because they felt they would not comprehend [18]. However, this still differs strongly from regularly misinforming patients, as observed here.

The power of the family, which becomes visible in this study, can be explained by cultural values and must also be considered an economic factor. Despite the already existing infrastructure, only about 50% of all the applicants can be accepted into residential homes [19], [20]. Although centers exist in Tirana and Shkodra, 62% of all Albanian municipalities do not offer any services for older adults [21].

Thus, most older people in Albania rely heavily on their families' social and economic support [22], [23]. This support and responsibility for the elderly are not necessarily interrupted when entering a care institution. Only in cases of abandonment or when families leave the country does the legal representation shift to the institutions.

Decision-making

In contrast, the patients' will is firmly considered in their daily nutrition, freedom of movement, and hygiene. It is consistent with the study's findings by Scott *et al.* (2003). Although a limitation of resources and staff puts many restrictions on the caring institutions, a higher level of autonomy is probably also a response to limited staff (Table 4).

Table 4: Overview of medium and low autonomy

High to medium level of autonomy	Low level of autonomy	
Nutrition	Medication	
Patients' tastes, religious diets,	Medication has to be accepted. A drug m	
and decisions not to eat are	be mixed into food	
frequently respected. Patients		
can, in some cases, cook for		
themselves		
Freedom of movement	Palliative care	
Patients are free to go out	Patients are misinformed about their	
independently, and isolation is	diagnosis, and decisions about the	
used sparingly	continuation of treatment do not include	
	patients	
Hygiene	Will to die	
Individual wishes about bathing	Patients' will to die is not taken seriously.	
times are considered legitimate	Rare cases of suicide occur	
Last rites	Introduction to institution	
Decisions on prior rights are taken	Families have the final decision over	
as essential and followed	entering care institutions. Applicants without	
	their family's consent are turned away	

The custom of not informing a patient about their diagnosis is especially highly problematic. Here, the nurses are in a difficult situation whenever supporting the patient's autonomy. They must compromise between the will of the family and the patient's wish, between the traditional power of relatives and the legal rights of the elderly. In many cases, in these interviews, the nurses try to agree with the family and instead influence them by advice than openly supporting the patient in their rights. This, of course, also reflects the fact that in conflicts between the elderly and the family, the latter is often more powerful and can cause problems for the medical staff even after the elderly deceased or left the institution. This family situation is pervasive in elder care, undermines the patients' decision-making ability and autonomy, and introduces doubt into the nurses' decisions [24].

Here, strengthening the patient's rights by written advanced directives would also empower the nurses to work openly on their behalf. However, since having advance directives is not a common occurrence for Albanian citizens, being a formerly paternalistic society, it might be difficult for the medical staff to get families and patients into practice [25].

Ethical Conflicts

Furthermore, the study indicated that knowledge about ethical or legal issues alone is insufficient to bring change. Although many interviewed lack a proper understanding of these concepts, they follow informal standards and have a subjective sense of appropriate behavior. Neglect of patients' consent, such as in eating or bathing, is not attributed to a lack of education but is often the result of a lack of staff. Therefore, sufficient resources play a critical role

in improving and applying standards in senior care institutions, an issue that is universal in elder care [26].

The study unveiled a generational difference between senior nurses with college degrees and younger nurses with a university diploma. While the latter proved more willing and were able to talk about ethical and legal issues, they, at the same time, reported social conflicts with families more frequently. However, also the type of caring institutions may play a factor here. The younger nurses were predominantly employed in the better-equipped private nursing homes, whereas the senior nurses mostly worked in underfunded public nursing homes. Here, further research is needed to understand better the relationship between experience, education, and type of institution regarding social conflicts in senior care.

A key finding of the study suggests that increased legal knowledge about patient rights could trigger conflicts with family members. Following this hypothesis, strengthening patient rights also means restricting (informal) rights of the family to decide on the elderly's behalf, which is often rooted in culture [27].

This conflict regarding patient rights and who makes the decisions regarding treatment is partly caused and intensified by the influences of Albanian culture. While religion is primarily considered to be unimportant, the role of the family cannot be stressed enough. Families play a crucial role in senior care. They are treated as the representatives of the patient far beyond their legal position, often at odds with the patient's wishes or without an official proxy [25].

The common practice of not informing patients with terminal illnesses of their diagnosis is a cause of significant conflict. According to modern standards in senior care, patients always have the right to know their diagnosis and make informed decisions about their treatment as far as possible. Albanian families do not readily accept such measures. Here, the patient is expected not to know their diagnosis for him to "live normally until the end." In contrast to western understandings of confidentiality, telling the patient their diagnosis is easily seen as lacking professional confidentiality. Nurses are often required not to communicate the diagnosis to the patient [28]. Increased legal knowledge by the staff and a willingness to implement such standards can lead to significant conflicts with the families. Therefore, legal and ethical understanding is required, and problem-solving skills to communicate legal requirements of patient rights to the families are needed.

Allow for patient autonomy at the end of life is a critical issue in geriatric care [5]. However, as this study shows, cultural values can alter the understanding of autonomy in the decision-making process. One pattern came up again in this study: Patients do not know their diagnosis at the end of their lives. Patients are intentionally kept uninformed or misinformed as

demanded by their families. By doing so, they are excluded from the decision-making process and kept naïve about their condition. They are expected to "live normally until the last day" [28].

Although nurses' education is improving in Albania, knowledge about patients' rights alone is insufficient to change this behavior. In the interviews conducted here, nurses with a university degree were aware of the principle of informed consent and the patient's right to know their diagnosis. However, this correlates with increased conflicts with the residents' families compared to their non-university-educated colleagues. Telling the patient their diagnosis against the family's will is a severe infringement of professional confidentiality. Instead, nurses try to convince families to inform the elderly or communicate the diagnosis nonverbally [8].

The study showed how implementing legal regulations and professional, ethical discussions (committees) through professional education could face serious resistance when confronted with values at odds with these laws. Strengthening the patient's legal rights at the end of their life also implies restricting the traditional rights of families to decide on the elderly's behalf. Here, legal education for nurses is needed as preparation for conflicts with the families and an increasing sensibility for the relatives of the elderly.

From the findings of this study, it is evident that offering education for family members and the elderly is essential for those considering nursing care for their older relatives. For nurses, ethical and legal education is needed regarding informed consent and patient autonomy, and conflict resolution with patients and their families so that geriatric patients receive the best care possible. Advance directives and living wills are options that the government must promote to ensure that decision-making for families and health-care professionals is less ambiguous.

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