# Abstract

**Background**: In recent years the number of patients hospitalized in intensive care units has increased steadily. Various invasive procedures are often performed on these patients, some of which are not done for the purpose of immediate life-saving, such as a tracheostomy. Since some of the patients are unconscious or under anesthesia, it is not possible to obtain their informed consent for performing invasive procedures. In Israel there is a legal process of appointing a health care proxy. With his or her appointment, the health care proxy is authorized to make decisions regarding medical treatment, including agreeing to or refusing an invasive treatment recommended by the doctors. At present, the intended proxy is required to appear in court to submit the application and receive the appointment (hereafter: physical approach). This study examines the standard appointment process compared to an appointment process that does not require appearing in court.

**Research goals** are as follows:

* To examine the opinions of health care proxies of intubated intensive care patients regarding the process of their appointment as proxies for the purpose of making decisions about performing invasive procedures on their relatives, procedures that are not for immediate life-saving purposes.
* To examine the opinions of hospital staff members and stakeholders regarding the process of the proxy’s appointment for the purpose of making decisions about performing invasive procedures that are not for immediate life-saving purposes.
* On the basis of these opinions, to formulate a sustainable proposal for changing the policy regarding a proxy’s appointment, in accordance with Lewin’s theory of power fields.

**Research tools:**

Quantitative branch: To conduct the study, a three-part questionnaire was written. The goal of the questionnaire is to examine the proxies’ opinions. The first part is a demographic questionnaire regarding the patient and the proxy. The second part is a subsection of the FS-ICU 34 questionnaire developed by Heyland and Tranmer (Heyland and Tranmer, 2001). This part checks the proxies’ satisfaction with the decision-making process. The third part is a questionnaire that examines the proxies’ opinions and their means of decision-making regarding patients in intensive care (ADMAP). This questionnaire was developed by the researchers for the present study. For more details, see Appendices A, B, and C.

The qualitative branch is comprised of a semi-structured questionnaire to the proxies (a section of the ADMAP questionnaire), a semi-structured questionnaire to the medical staff (nurses and social workers), and in-depth interviews with stakeholders. For more details, see Appendices C and E.

**Study population:** Health care proxies of intubated intensive care patients; staff: nurses and social workers; and stakeholders who participated in in-depth interviews: doctors, nurses, social workers from various intensive care units, hospital directors and Ministry of Health officials, legal advisors to medical centers, and jurists familiar with the process.

**Research method:** The study integrates quantitative and qualitative approaches (mixed method research). The quantitative branch examines the opinions of proxies in two different groups, in a research format of pre/post intervention. In this study, the intervention is changing the proxy appointment process, such that the intended proxy is not required to appear in court himself or herself in order to obtain the appointment. The control group (before intervention) is the group of proxies who are required to appear in court in order to apply for and receive the appointment (“physical approach”). The intervention group is the group of people who were appointed as proxies without having to appear in court. This group applied to the court via fax, with the help of the social worker and the medical center’s legal advisor who participated in the study (“mechanical approach”). Both groups answered identical questionnaires evaluating their satisfaction with the appointment process and the decision-making, as well as a demographic questionnaire.

The qualitative branch of the study includes several components. The proxies answered a semi-structured questionnaire intended to more broadly and thoroughly examine their opinions about the appointment process. In addition, to ensure a complete picture from the study, relevant staff members (nurses and social workers) were asked for their opinions regarding the difficulties that proxies face during the appointment process. In-depth interviews were also carried out with stakeholders (doctors, nurses, and social workers in intensive care, administrators in the health system and jurists knowledgeable about the process) to investigate the process thoroughly. These interviews were also intended to examine the need to make changes in the existing policy and its application, and to identify which forces support introducing a change and which forces oppose it. The quantitative findings underwent content analysis in an attempt to identify recurring themes in the respondents’ answers (proxies and staff members), as well as parties that support instituting changes and parties that oppose it. These conclusions lead to proposing solutions that will reduce the resistance to changing the appointment process.

The study was conducted at two large medical centers in the center of the country, and approved by the institutional Helsinki committees. The pilot study included 12 respondents from the group of the physical approach to the court (before intervention). The study population included the control group (appointment by physical approach to the court) and the intervention group (appointment by mechanical approach to the court). Ninety-six respondents from two medical centers participated in the control group: 32 respondents from one medical center and 64 respondents from the second one (in which, after some time, the change was made and the intervention group was recruited). Sixty four respondents participated in the intervention group (from one medical center).

In order to gain a thorough understanding of the issue, relevant staff members (nurses [N=34] and social workers [N=14]) were asked about the difficulties that they believed the proxies faced in the standard appointment process (physical approach). In addition, 20 in-depth interviews were conducted with stakeholders in order to evaluate the process thoroughly and identify obstacles that might hinder the introduction of changes to the appointment process. A content analysis was conducted to identify the parties encouraging introduction of the process change, as well as parties hindering its introduction. This was in order to propose solutions that would reduce resistance to the process.

**Findings**:

The quantitative branch: It was found that the only reason for appointment of the proxy was the need to perform a tracheotomy. A negligible difference in demographic variables was found between the intervention and control groups. No significant differences were found in the qualitative questionnaires (ADMAP, FS-ICU). On a small number of questions (3 statements in the two tools, which together included 25 statements, after applying a Bonferroni correction for multiple comparisons), a significant difference was found between the two groups, but this difference did not lead to overall significance of the questionnaires. On all the statements in which significant differences were found between the groups, the intervention group’s opinion of the process was more positive; compared to the control group, the intervention group received more information, felt that they had more control over the care of the family member, and felt more satisfaction with the decision-making process.

The qualitative branch: Analysis of the qualitative component of the proxies’ responses brought out three central issues which present obstacles for the proxies: the logistical-bureaucratic sphere, family difficulties, and emotional difficulties. It is important to note that in the intervention group (mechanical approach), the bureaucratic issue occupied a more marginal place than in the control group (physical approach). The other two difficulties, family and emotional, were significant for both groups.

Analysis of the staff members’ responses showed a gap between opinions of the nursing staff and those of the proxies and the social workers. The social workers and proxies presented the logistical and bureaucratic issue, the family difficulties, and the emotional difficulties as central problems. The nursing staff, in their responses to questions about obstacles the proxies faced during the appointment process, also raised the issue of family and emotional difficulties, but did not raise the bureaucratic issue at all.

An analysis of the in-depth interviews with stakeholders found that they agree on the need to change the current system. Moreover, they emphasized the importance of defining an orderly and official appointment process. The interviewees expressed broad support for the proposed change in the appointment process, identified forces that were expected to support the change or oppose it, and proposed ways to involve these forces in promoting the change.

**Discussion**: This study is the first of its kind to examine the process of appointing health care proxies, a process which has existed in its current form for the past 25 years. The study found that in all cases examined, the indication for appointing a health care proxy for an intensive care patient was the need for a tracheotomy. This finding indicates that other procedures such as pulmonary or gastrointestinal endoscopy are less common in intensive care, or else are performed as urgent procedures with no need for the appointment of a health care proxy.

The findings depict the proxy appointment process as a complex one, requiring more thorough investigation. In the quantitative branch of the study, no significant differences were found. This can be explained by the great complexity of the process; although a certain difficulty in the appointment process changed, it did not disappear. The qualitative findings demonstrate the full complexity of the process. In this part of the study, three central issues were found: (1) a logistical-bureaucratic difficulty; (2) a family difficulty; and (3) a personal difficulty of the proxy. In the latter two difficulties one can see universal hardships stemming from the situation in which the patient and his family find themselves. The change to the appointment process that was made in the framework of this study (the move to a mechanical approach) is intended primarily to alleviate the bureaucratic difficulty, and it is true that the intervention group sees it as a marginal issue. Meanwhile, the family and personal difficulties remained clear. Thus the proposed change does not resolve all the obstacles that proxies face during the appointment process, and therefore the quantitative findings are not significant.

An additional finding of the study is the fact that the nursing staff is not aware of the complexity of the process and the bureaucratic obstacles faced by the proxies. This lack of awareness apparently stems from the fact that the nurses are not involved in the bureaucratic processes, which are generally led by the social worker, with involvement of the attending physician. Yet, it is very important that the nurses be aware of these difficulties, given that the nurses are the staff most accessible to the proxy; they are the ones to provide directions, training, and explanations on a wide range of issues, and serve as the first address for meeting the needs of the proxy and the family members in the hospital.

**Conclusions**: The study thoroughly examined the complex process of appointing a health care proxy. The study produced findings which demand ongoing and even more thorough investigation in order to improve the process in its present form, as it has existed for some 25 years. Although the proposed change that was investigated does not resolve all the difficulties, it can definitely help health care proxies in dealing with one of the obstacles they described in the study (the logistical-bureaucratic difficulty). In the framework of the study, identification was made of forces that support the change and forces that oppose it, and the findings were analyzed in depth to encourage support for the change and reduce the resistance to it, according to Lewin’s theory of force field analysis. Identifying these forces enables us to determine that our proposal for changing the appointment process met with broad support from the proxies and stakeholders. In light of these findings, it may be stated that the proposal for change is feasible and sustainable. Along with introducing the change, a thorough examination of the overall process is needed in order to find solutions for additional difficulties identified by this study. An important aspect of force field theory that comes out of this study is that in complex processes, involving many partners and stakeholders, one change is not necessarily enough to resolve the complexity and the many difficulties existing in the process. Each change is a complex process in itself; this is even more true when trying to change a complex process, which requires thorough planning all along the way. It may turn out that step-by-step intervention will be needed, involving several stages, in order to ensure that the difficulties and complexity are handled appropriately and the optimal solution identified.

Our recommendation to the nursing staff is to increase awareness of the complexity and bureaucratic and logistical obstacles faced by health care proxies as long as the appointment process continues in its present form. Incorporating the topic in the nursing study curriculum, along with task-oriented training and workshops, as well as more active involvement of the nursing staff in the appointment process, will all help raise awareness of the issue.

In summary, our study highlights significant problems with the processes of decision making, appointing health care proxies, and giving informed consent on someone else’s behalf. At the same time, we offer applicable and feasible solutions to some of the problems raised. Without a doubt, the Corona pandemic dramatizes the need to find more accessible and easier solutions for everything related to the issues we have investigated, and thus underscores even more clearly the importance of our study.