# Abstract

**Background**: In recent years, there has been a steady increase in the number of patients hospitalized in intensive care units. These patients often have a variety of invasive procedures performed on them. Emergency life-saving procedures do not require informed consent, but other commonly performed but non-emergency life-saving procedures, such as tracheostomies, do require such consent. Since some of the patients are unconscious or under anesthesia, it is not possible to obtain their informed consent for performing these non-emergency but nonetheless invasive procedures. Israel has a legal process for appointing a legal guardian (LG) health care proxy in such situations. Once appointed, the health care proxy is authorized to make decisions regarding medical treatment, including authorizing or refusing an invasive treatment recommended by the doctors. Currently, the proxy candidate is required to physically appear in court to submit an application and receive the health care proxy appointment from the court. This study examines today’s standard appointment process and compares it to an appointment process that does not require a court appearance.

**Research Goals**

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

**Research Tools**

Quantitative research tools: To conduct the study, a three-part written questionnaire was designed to obtain the LGs’ opinions about the appointment process. The first part is a demographic questionnaire seeking details about the patient and the LG. The second part is a subsection of the FS-ICU 34 questionnaire developed by Heyland and Tranmer (Heyland and Tranmer, 2001) which examines the LGs’ satisfaction with the decision-making process. The third part is a questionnaire developed by the researchers for the present study to ascertain the proxies’ opinions about the process and their means of decision-making regarding patients in intensive care (ADMAP). For more details, see Appendices A, B, and C.

The qualitative research tools included a semi-structured questionnaire for the LGs (a section of the ADMAP questionnaire), a semi-structured questionnaire for the medical staff (nurses and social workers), and in-depth interviews with stakeholders. For more details, see Appendices C and E.

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

**Research method:** The study integrated quantitative and qualitative approaches (mixed method research). The quantitative facet examined the opinions of LGs in two different groups, in a research format of pre/post intervention. In this study, the intervention was changing the LG appointment process, such that the intended LG was not required to appear in court personally in order to obtain the appointment. The control group, pre-intervention, was the group of LGs who were required to appear in court in order to apply for and receive the appointment (“physical approach”). The post-intervention group was the group of people who were appointed as LGs without having to appear in court. Instead, this group applied to the court for the appointment 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.

There were several components of the qualitative facet of the study. The LGs answered a semi-structured questionnaire intended to thoroughly examine their opinions about the appointment process. In addition, in order to obtain a more comprehensive understanding of the process, relevant staff members (nurses and social workers) were asked for their opinions regarding the difficulties that LGs 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) in order to thoroughly investigate the process. These interviews were also intended as a tool for analyzing the need to make changes in the existing policy and its application, and to identify forces and parties in favor of introducing change in the appointment process and those opposing any such change. The quantitative findings underwent content analysis in an attempt to identify recurring themes in the answers of LGs and staff members, as well recurring themes among parties supporting and opposing changes in the appointment process. The conclusions drawn from these findings can contribute to the formulation of 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 was approved by the institutional Helsinki committees. First, a pilot study was conducted which included a control group of 12 respondents who had been appointed by “physical approach” (pre-intervention group), and the intervention group, consisting of respondents appointed after approaching the court by technical means.

In the actual study, 96 respondents from two medical centers participated in the control group: 32 from one medical center and 64 from the second one. Subsequently, the 64 respondents from the second medical center were recruited to participate in the post-intervention group.

In order to obtain a comprehensive understanding of the issue, relevant staff members (nurses [N=34] and social workers [N=14]) were asked about the difficulties that they believed the LGs 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 supporting introducing changes to the appointment process, as well as those parties opposing changes. The purpose of this analysis was to help formulate solutions that would reduce resistance to the process.

**Findings**

***Quantitative:*** Among the study group, it was found that the only reason for appointing a LG was to obtain approval to perform a tracheotomy. A negligible difference in demographic variables was found between the intervention and the control groups. No significant differences were found in the responses to the qualitative questionnaires (ADMAP, FS-ICU). On a small number of questions (three 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 any overall significant difference between the results of the questionnaires. Among those statements in which significant differences were found between the groups, the post-intervention group’s opinion of the process was more positive. Compared to the control group, the post-intervention group received more information, felt that they had more control over the care of the family member, and experienced more satisfaction with the decision-making process.

***Qualitative***: An analysis of the qualitative component of the LGs’ responses revealed three central areas in which the proxies experienced challenges: the logistical-bureaucratic sphere; family difficulties; and emotional difficulties. It is important to note that in the post-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 revealed a gap between the opinions of the nursing staff and those of the LGs and the social workers. For the social workers and LGs, the logistical-bureaucratic issue, and the family and personal emotional difficulties were experienced as central problems in the appointment process. In contrast, the nursing staff, while acknowledging the family and emotional difficulties, did not raise the logistical-bureaucratic issue at all.

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

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

The findings indicate that the proxy appointment process is indeed complex and is in need of more thorough investigation. In the quantitative findings, no significant differences were found between the groups. This may be attributed to the great complexity of the process; although a certain amount of difficulty in the appointment process did change, the difficulties were not eliminated. The qualitative findings demonstrate the full complexity of the process, revealing three major challenges faced by those involved in the LG appointment process: logistical-bureaucratic difficulties; family difficulties; and the proposed LG’s personal emotional difficulties. The two latter areas of difficulties reveal the universal hardships arising from the situation in which the patient and the family find themselves. The primary purpose of this study’s proposed change in the appointment process, shifting it to a mechanical approach, is to mitigate the logistical-bureaucratic difficulties, Indeed, the post-intervention group which used the mechanical approach viewed the logistical-bureaucratic issue as a marginal one, although they, too, clearly experienced family and personal difficulties. Thus, the proposed change to a mechanical approach does not resolve all the obstacles that LGs face during the appointment process, and, therefore, the quantitative findings are not significant.

An additional finding of the study is that the nursing staff is not aware of the complexity of the process and the bureaucratic obstacles faced by the health care proxies. This lack of awareness apparently is a result of the nurses not being involved in the bureaucratic processes, which are generally directed by the social worker, with some involvement of the attending physician. Yet, given that the nurses are the staff most accessible to the proxy, providing the guidelines, guidance and explanations on a wide range of issues, and also serve as the first point of contact for meeting the needs of the LG and the family members in the hospital, it is very important that the nurses be aware of the difficulties LG face.

**Conclusions**: The study thoroughly examined the complex process of appointing a LG for patients in intensive care units. The study’s findings indicate the need for a further, even more thorough investigation in order to improve the present process, which has not changed for nearly 25 years. Although the proposed change that was investigated, , does not resolve all the difficulties, it can certainly help LGs better cope with one of the main challenges they identified in the study of logistical-bureaucratic difficulties. In the framework of the study, forces both supporting and opposing the proposed change were identified, and the findings were analyzed in depth according to Lewin’s theory of force field analysis in order to determine ways to encourage support for the change and reduce resistance to it. Identifying these different forces revealed that our proposal for changing the appointment process met with broad support from the LGs and stakeholders. In light of these findings, it may be concluded that the proposal for change is feasible and sustainable.

Along with introducing the proposed change, a thorough examination of the overall process is needed in order to find solutions for the additional, more personal, difficulties identified in this study. An important aspect of force field theory that emerges from 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 at every stage. Ultimately, step-by-step intervention may be needed, involving several stages, in order to ensure that the difficulties and complexity are handled appropriately and that the optimal solution is identified.

It is recommended that the nursing staff increase its awareness of the complexity of the current health proxy appointment process and the logistical and bureaucratic obstacles faced by health care proxies in navigating the process in its present form. Incorporating the topic into the nursing study curriculum, together with task-oriented training and workshops, and greater involvement of the nursing staff in the appointment process, will all help raise awareness of the issue.

In summary, this study highlights significant problems with the decision-making process, LGs appointment and giving informed consent on someone else’s behalf, and offers applicable and feasible solutions to some of the problems identified. Undoubtedly, the corona pandemic dramatizes the need to find more accessible and easier solutions for all the challenges involved in these issues, thus even more clearly underscoring the importance of this study.