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# Improving Health Literacy: Parental Medical Decisions Regarding Lower Extremity Amputations

By Rebecca Aber

## *Author Note*

This was prepared for Honors 200, Section 704, taught by Professor Mary Boyes

## *Abstract*

There are currently several injury severity scores, such as the LSI, MESI, MESS, and PSI that are used in the United States to form recommendations for limb amputation or reconstruction. These scores are based on data from adults, yet they are used for patients of all ages. Because parents with limited health literacy tend to make less informed medical decisions for their children regarding amputations, a pediatric version of a current injury severity score would help to guide these medical decisions. The pediatric version would be created from a pre-existing score by redesigning the variables used within the score. The Predictive Salvage Index (PSI) was the most viable score for pediatric use. This was due to its levels of sensitivity, specificity, and its simplicity when compared to other scores such as the Mangled Extremity Severity Score (MESS) and Mangled Extremity Score Index (MESI). After examining data based on children that correlated with the variables used in the PSI (level of arterial injury, degree of bone injury, degree of muscle injury, and interval of time from injury to operating table), suggestions were made to shift the amount of points patients were assigned by the PSI, creating a more accurate recommendation for pediatric patients. Using this pediatric version of the PSI, a decision-making protocol could then be implemented into health care systems as a way to help parents when making medical decisions for their children regarding amputations. Since one in four parents are found to have limited health literacy of some kind in the United States, this protocol is recommended to address low health literacy.

## *Introduction*

When a child breaks her femur, her parents are responsible for making quick medical decisions that affect the rest of her life. They have to make the decision to try and splint the leg themselves, to give her an ice pack or not, to take her to the hospital. These decisions determine how well the leg will be able to heal and function. Parents have always had a responsibility to make the best decisions they can for their children. They have been the deciders concerning smaller decisions such as what kind of food to have in the household and the deciders concerning much larger decisions, such as whether their child should receive vaccinations or certain surgeries.

Yin, Johnson, Mendelsohn, Abrams, Sanders, and Dreyer reported that one in four parents have limited health literacy of some kind (296). Not being able to comprehend health-related information, these parents have made less informed medical decisions for their children, specifically regarding amputations. According to the United States Department of Health and Human Services there were several proposed strategies that could be used to improve health literacy such as simplifying written information and improving communication between parents and doctors (10).

If levels of health literacy in parents were to continue to decrease in the United States, poor health of both parents and their children would increase. According to Yin et al. rural areas had higher numbers of parents with low health literacy. Within these rural areas, it would be extremely beneficial to have a decision-making protocol in place regarding amputations to improve health literacy and the medical decisions made by parents. By taking a pre-existing injury severity score and redesigning it for pediatric use, doctors would be able to more accurately recommend reconstruction or amputation of lower extremities in pediatric patients. Using these recommendations parents would be better guided in their medical decision-making.

### *Problems Associated with Low Health Literacy*

The U.S. Department of Health and Human Services claimed that majority of the time people are making medical decisions on their own. They have to decide what type of health insurance to use, what amounts of medicine to give to their children, and how to respond to the outbreak of diseases (3). Yin et al., conducted a study that examined the number of adults in the United States with limited health literacy and how their limited health literacy linked to poor health knowledge, poor health behaviors, and increased costs in healthcare. Yin et al. observed that, “1 in 4 parents, or 21 million U.S. parents have limited health literacy skills” and, “only 1 in 7 parents are categorized as having proficient health literacy.” Yin et al. noted that having an uninsured child and difficulty understanding OTC medication labels were independent of low health literacy in parents (s296).

According to the 2013 U.S. census, 12.9% of the rural U.S. population did not have health insurance, and 7.6% were children without health insurance (10). In a study conducted by Schillinger et al., health literacy levels were compared to diabetic outcomes in patients. While low health literacy was found to be independent of whether a child was insured or not, parents with higher levels of health literacy had a tendency to make better-informed medical decisions for their children and themselves, for example, being able to decrease the amount of problems associated with diabetes. Schillinger et al. reported that while low health literacy levels were independently associated to glycemic control and rates of retinopathy; it did contribute to having diabetes-related problems (475).

The statistics that Yin et al. reported can be compared to the number of children receiving amputations in the United States. According to Ziegler-Graham et al., roughly 185,000 people in the United States undergo amputations every year (422). According to the Center for Disease Control of these 185,00 amputees, 4,331 are under the age of 15 (17). According to Ziegler-Graham et al., with roughly half of the patients under the age of 15 living in rural areas (21), which according to Yin et al. had higher levels of low health literacy when compared to the rest of the United States, it is important to improve decision-making in health care settings specifically for amputations. Improving health literacy will help to improve the quality of decisions that parents will make for their children regarding amputations.

### *Strategies to Combat Low Health Literacy*

The U.S. Department of Health and Human Services emphasized how the standards that are beginning to develop for health care organizations are used to assess their performance and improve health literacy (7). It has been difficult in the past to calculate the health literacy levels throughout the U.S.; however in 2003, the National Assessment of Adult Literacy (NAAL) studied health literacy, and their data indicated that low health literacy affected nearly nine out of ten English-speaking adults in the United States (8).

Yin et al. conducted a study that involved asking parents questions to reveal their levels of

health literacy. They observed that of the parents who were incorrect when completing tasks to measure health literacy, 65.9% could not calculate the price per year of an insurance policy, 54.1% could not determine what a healthy weight range for someone would be when shown a chart with the information, and 39.9% could not determine when a child should receive their third hepatitis B vaccination when given a chart showing all vaccines and the ages children should receive them (s294). These examples all involved reading charts or graphs to calculate or figure out certain information. The U.S. Department of Health and Human Services declared that adults with low health literacy, specifically those below basic health literacy, had issues reading charts or simple instructions. These same adults were more likely to report that their health was poor as well (9).

Innovative approaches to improve health literacy as emphasized by the U.S. Department of Health and Human Services were becoming evident through the fields of communication, health care, public health, and adult education. The U.S. Department of Health and Human Services claimed that there were several goals or strategies that could be used to improve health literacy. These strategies were to develop accurate health and safety information, promote changes in health care systems, incorporate accurate information in child care and education, support and expand efforts to provide education, build partnerships, increase research, and increase dissemination and use of evidence based health literacy practices. For example, the U.S. Department of Health and Human Services observed that many of the strategies used to address low health literacy stemmed from the fields of communication, health care, public health, and adult education. One way of combatting low health literacy was to improve written materials. A possibility was using videos or pictures alongside the written information to augment it, or to improve communication between a doctor and a patient, or parent (10).

The U.S. Department of Health and Human Services recommended using these strategies not as solitary pieces, but as an “integrated approach” to improve health literacy (22). Yin et al. agreed with The U.S. Department of Health and Human Services that efforts should be made to decrease the literacy demands put on parents so they can better address the health needs of their children. Yin et al. suggested looking further into the design of written materials such as health insurance forms and medication labels (s297). To improve parental medical-decision making regarding amputations for pediatric patients, an injury severity score was created for pediatric use from a pre-existing score. This score has been developed for the use of doctors to create recommendations for either amputations or reconstructions and would then be used to guide parental decision-making.

### *Current Injury Severity Scores*

There are several different injury severity scores currently being used in the United States: the MESI, Predictive Salvage Index (PSI), Limb Salvage Index (LSI), the MESS, the Nerve injury, Ischemia, Soft tissue injury, Skeletal injury, Shock, Age system (NISSSA), and the Hannover Fracture Scale 1998 (HFS-98). All of these scores included amputation thresholds, which determined whether a patient should be recommended for amputation or limb reconstruction. The data used to create these scores was based on data from adults, leading the outcomes of these scores to be inaccurate for children.

In research reported by Stewart, Coombs, and Graham, sensitivity of the patients, or the probability that the patients would receive amputations, would have scores at or above the amputation threshold. Stewart, Coombs, and Graham recorded specificity as well, which was the exact opposite of sensitivity, and how likely a patient was to be below the threshold (428).

Bonanni, Rhodes, and Lucke observed that assigning a point system to the injury severity

of each organ system contributed to the development the MESI. Shock, ISS, age, comorbid disease, and lag time were used as variables for the point system. Bonanni, Rhodes, and Lucke researched the MESS as well(101). The MESS also used a point system, but was based on four areas of clinical criteria (skeletal/soft-tissue injury, limb ischemia, shock, and age). Mommsen et al. described how the MESS was originally developed in 1990. The MESS used a scoring system that classified anything that was above or equal to the threshold of seven as likely for amputation, anything under predicted limb salvage (2).

The PSI was developed by Howe et al. and was based on a scale of three to thirteen. Level of arterial injury worked on a scale from one to three, or suprapopliteal to infrapopliteal. One was least likely to be recommended for amputation while three was most likely to be recommended for amputation. Degree of bone injury and degree of muscle injury worked in the same way, although their scale went from mild to severe. Interval before surgery was on a scale from zero to four. Zero points were given to patients who had been injured in the last six hours, two points were given to patients who had been injured in the last six to twelve hours, and four points were given to patients who had been injured more than twelve hours ago. A score greater than or equal to eight was recommended for amputation, while a score less than or equal to seven was recommended for limb salvage (205).

#### *Why the MESI and MESS Are Not Viable*

Although there were many different severity scores in use, none were based on pediatric data. Stewart, Coombs, and Graham claimed that current injury severity scores such as the LSI, MESS, PSI, NISSA, and HFS-98 were based on data from adults and therefore could not be used interchangeably for pediatric patients (427). In order to make more accurate medical decisions for pediatric patients regarding amputations, a current score was redesigned. The best score to be redesigned for this purpose was the PSI. Although they have been claimed to be viable, neither the MESS nor the MESI had merit for pediatric use. Because of the great difference between upper and lower extremity injuries and limb salvage concerning the MESS, and the fact that it was primarily based on data from adults, it was not viable. The MESI had certain factors that were inflated due to variables being derived from small sample sizes; this caused the MESI to have a low sensitivity and a high specificity, leading the MESI not to be recommended for pediatric use.

Mommsen et al. claimed that when treating pediatric patients the MESS scoring system could be used to decide whether to salvage a limb or to amputate. Mommsen et al. supported this by reporting that traumatic extremity pediatric vascular injuries were very rare, and that the most common cause of traumatic vascular lesions for children were penetrating injuries and fractures. For this reason, he supports the MESS to be appropriate for use when making decisions regarding amputations for children (1). However, Mommsen et al. noted that the value of the MESS being used for decision making with children was debatable due to the fact that a vast majority of the current available studies pertained only to adults (2). Stewart, Coombs, and Graham agreed with Mommsen et al. by stating that while current injury severity scores are based on data from adults, there was not much data available on the use of those scores in pediatric patients, supporting their claim that current injury severity scores should not be used on pediatric patients in their current format (427).

Another reason the MESS was not be feasible for pediatric use was that Mommsen et al. observed that there was a great difference between upper and lower extremity injuries concerning the MESS and limb salvage. Injuries of lower extremities were found to have much more severe injuries than those of the upper extremities. The MESS scores for patient's upper extremity injuries were never equal to or greater than seven, leading all upper extremity injuries to be

recommended for limb salvage (4). Stewart, Coombs, and Graham contended “The MESS and NISSSA both use age itself as a scoring criterion, thus making differentiation between pediatric patients impossible” (430). Both the MESS and NISSSA categorized pediatric patients as less than thirty years of age, however according to the American Academy of Pediatrics, in the United States a patient is considered pediatric only up to the age of twenty-one (736). This decreased the accuracy of recommendations produced by the MESS and NISSSA for pediatric patients.

Bonanni, Rhodes, and Lucke reported that although the variables used in the MESI had merit, they were inflated because they were derived from small sample sizes, causing the MESI to have a low sensitivity and a high specificity. This was why Bonanni, Rhodes, and Lucke claimed that the MESI was only able to predict the most extreme injuries. Another reason was that Bonanni, Rhodes, and Lucke observed that the MESI had many variables, for example the ISS (injury severity score) of organs, making it more complex than other scores (102).

### *Why the PSI is Viable for Pediatric Use*

The PSI was less complex than scores such as the MESS and MESI and had a more accurate specificity and sensitivity than the other severity scores. Because of this, it was viable for pediatric use. Stewart, Coombs, and Graham conducted a study that applied severity scores such as the PSI and MESS to pediatric patients over a ten-year period (427). Stewart, Coombs, and Graham claimed that a majority of the scoring systems used in their study had a poorer specificity than the PSI. With all of the patients in the analysis included, the PSI achieved 90% specificity, dropping to only 87% when only tibial trauma was looked at. The specificity was “greater than that shown when an adult population was considered” (430).

Bonanni, Rhodes, and Lucke observed that in their study the specificity for the PSI was 100% and the sensitivity was 78%. This was more impressive when compared to the MESI’s specificity of 90% and sensitivity of 6%. Bonanni, Rhodes, and Lucke observed that with fewer variables, the PSI was much less complex and accounted for data more appropriately (102). Bonanni, Rhodes, and Lucke noted that the way the variables of the PSI were graded, for example, degree of muscle injury scale from mild to moderate to severe were difficult to interpret (103). However, both the MESS and NISSSA used the same scale to measure ischemia, the only difference being the addition of “none” at the beginning of the scale, and the PSI defined “mild,” “moderate,” and “severe” for each variable it covered so as to decrease confusion of this kind.

Durham, Mistry, Mazuski, Shapiro, and Jacobs agree that the MESI is complex and difficult to apply. That is also requires information that may not be available until all of the patient’s injuries have been identified. It has been criticized for not giving enough weight to ischemia time and to soft tissue injury, both of which are major prognostic indicators of outcome. Both of these important variables, time interval and muscular injury, are included in the PSI. Durham et al. also noted that the MESS and PSI were simpler scores in comparison to MESI (573). This was due to both scores having fewer variables than the MESI.

The variables that the PSI used were also more applicable to pediatric patients than variables used in other scores such as age and shock. Unlike the MESS and NISSSA, the PSI did not account for age when making recommendations. This increased its accuracy in pediatric patients by not combining pediatric and adult patients under the same category of less than thirty years of age. The PSI also did not account for levels of shock. Stewart, Coombs, and Graham emphasized that one of several problems when applying current severity scores to pediatric patients was that the “MESS, NISSSA and HFS-98 also make use of an evaluation of shock. All three systems specify specific values for systolic blood pressure which are inappropriate in the light of normal values in children” (430).

### *Anatomical and Physiological Differences Between Children and Adults*

Taking into account that all current severity scores are based on data collected from adults, the variables involved in the PSI (level of arterial injury, degree of bone and muscle injury, and interval of time), were reassessed using pediatric data to improve the PSI's scoring system. Stewart, Coombs, and Graham reported, "Currently available injury severity scores behave differently in children and adults. In their current format, these scores should not be used as an absolute indication for early amputation in children" (428).

Kelly, Davis, Justice, Miller, and Nelson claimed that children with limb deficiencies had different problems when compared to adults. Kelly et al. emphasized that children experienced "often rapid changes" in growth, neurologic development, muscle strength, skeletal alignment, center of gravity, and gait from birth to skeletal maturity (196). Mommsen et al. reported that when it came to children's vascular injuries, complications were portrayed by the specific differences in pediatric and adult anatomy and physiology. Mommsen et al. observed that vascular injuries in children were typically characterized by "small and thin-walled vessels," with "poor tissue support," and "pronounced tendency to vascular spasm" when compared to adults (1).

### *Pediatric Adjustments to the PSI*

Based on the conclusion of Mommsen et al., Kelly et al., and Stewart, Coombs, and Graham that children and adults had multiple anatomical differences and the conclusion based on the research conducted by Bonanni, Rhodes, and Lucke and Stewart, Coombs, and Graham (2012) that the PSI was the most promising injury severity score for pediatric use, the variables within the PSI were then changed for pediatric use. According to Bonanni, Rhodes, and Lucke "[The PSI] incorporates four variables: level of arterial injury, degree of bone injury, degree of muscle injury, and interval from injury to operating room" (102).

The first aspect, level of arterial injury, was much more different in adults than in children. By looking at the difference between adults and children, the variable was shifted accordingly. Mommsen et al. reported that arterial injuries were found to be more complicated in children than adults and typically were identified by their "small and thin-walled vessels", "poor tissue support", and the tendency to have "vascular spasm" (1). In a study that identified patterns of injury related to pediatric vascular trauma, Klinkner, Arca, Lewsi, Oldham, and Sato affirmed that injuries to the pediatric artery displayed "spasm, an intimal tear, bleeding from a geniculate artery, occlusion of the posterior tibial artery, and a traumatic basilar artery aneurysm" (180). Ogden confirmed that vascular spasm and swelling of arterial injuries are seen in pediatric patients (313).

Accounting for this, arterial injuries in children should be treated more carefully due to their fragility. Arterial injuries in adults were found to be more stable in children, leading the pediatric version of the PSI to assign more points to children for arterial injuries than adults.

According to Frick, when compared to adults, children's skeletal injuries had a need to be treated as early as possible. This was due to the fact that they healed much more quickly. If not treated quickly enough, certain injuries would damage growth mechanisms severely, causing them to never recover and the bone to never heal properly (14). Ogden contended that, "Traumatized children generally develop fewer generalized or bone-specific complications than adults with comparable musculoskeletal injuries. Even when children do develop complications, the problems tend to be less severe and more rapidly overcome than those in similarly involved adults" (311). The point system for bone injuries stayed the same; however, the interval of time before surgery was shifted by increasing the amount of points a pediatric patient received. This increased the likeliness that a pediatric patient would receive an amputation and accommodated for the fact that for pediatric patients to successfully recover the use of an in-

jured limb, skeletal injuries must be treated as soon as possible. Increasing the amount of points a pediatric patient received for interval of time before surgery also benefited the treatment of arterial injuries. Ogden noted that delaying the diagnosis of arterial injuries lessens the opportunity to salvage extremities (313).

After researching the structures of muscles in children and adults, O'Brien, Reeves, Baltzopoulos, Jones, and Maganaris contended that fascicles, muscles, and tendons "lengthen proportionally during maturation" (631). This led O'Brien et al. to contend that "muscle-tendon stiffness" and "excursion range" (631) was likely to be similar in both children and adults. Reeves et al. noted that the only major difference between pediatric and adult musculature was the force production, which was found to be greater in adults. (631) Davies, White, and Young affirmed this by finding that the "absolute differences" of muscles in children and adults was the strength and "function of muscle mass" (111). Due to the similarity of muscle structure in children and adults, degree of muscle injury did not need to be changed in any way.

*An Overview of the Pediatric Version of the PSI*

The pediatric version of the PSI is recommended for implementation into hospitals through a decision-making protocol. Doctors would use the pediatric version of the PSI and this protocol to help guide parents in the decision-making process. The pediatric version of the PSI would have the same amputation threshold but assign points differently than the current PSI. The decision-making protocol would be created in a way that accounted for limited health literacy in the U.S. by making the information accurate and easy to comprehend and keeping an open line of communication between the healthcare providers and the parents.

The current version of the PSI, shown in table 1, can be compared to the pediatric version shown in table 3. For pediatric use, the PSI was changed based on the data observed. The pediatric version of the PSI works on a scale of two to four for the level of arterial injury, one to three for the degree of bone injury and degree of muscle injury, and one to five for the interval before surgery. According to research conducted by Stewart, Coombs, and Graham, it is recommended to not change the pre-existing amputation threshold. "In our study, raising the MESS amputation threshold would not increase specificity and would also reduce sensitivity. Similarly, raising the threshold of the PSI would not increase specificity and would reduce sensitivity to zero" (430). The threshold was kept the same for the pediatric version of the PSI, with a score of eight or higher being recommended for amputation and a score of seven or lower being recommended for limb salvage.

Current PSI		
Level of Arterial Injury	Suprapopliteal	1
	Popliteal	2
	Infrapopliteal	3
Degree of Bone Injury	Mild	1
	Moderate	2
	Severe	3
Degree of Muscle Injury	Mild	1
	Moderate	2
	Severe	3
Interval before surgery	<6 Hours	0
	6-12 Hours	2
	>12 Hours	4

*Table 1*

Pediatric Version of PSI		
Level of Arterial Injury	Suprapopliteal	2
	Popliteal	3
	Infrapopliteal	4
Degree of Bone Injury	Mild	1
	Moderate	2
	Severe	3
Degree of Muscle Injury	Mild	1
	Moderate	2
	Severe	3
Interval before surgery	<6 Hours	1
	6-12 Hours	3
	>12 Hours	5

*Table 2*



This would not be the first time an index or score was redesigned for pediatric use. Jewell, Carr, Stratton, Lask, and Eisler reported that the Systematic Clinical Outcome and Routine Evaluation (SCORE) Index of Family Function and Change could be changed for the use of children under the age of 12. Although the SCORE and PSI have many differences, the system used to change the SCORE was applied to the PSI. Jewell et al. broke the SCORE down into its three phases and then used data based on children to make changes to the phases and other variables involved in the SCORE in order for a pediatric version of the SCORE to be developed (674). The same basic idea was used when the PSI was broken down into its four variables and redesigned using pediatric data.

Another example of a score or index being redesigned was the development of the NISSA. Although this score was not designed for pediatric use, its authors did take a pre-existing injury severity score and shift it to create more accurate recommendations. According to Stewart, Coombs, and Graham the NISSA was developed from the MESS by adding variables such as nerve injury (428).

### *Conclusion*

This pediatric version of the PSI is recommended for use in any hospital that handles the care of pediatric patients undergoing amputations. More specifically, the pediatric version of the PSI should be implemented into areas with lower health literacy. Yin et al. reported that rural areas were shown to have the highest health illiteracy rates in the United States (s295). The U.S. Department of Education claimed that in 2004 more school-age children in rural areas had parents who completed high school as their highest level of education when compared to school-age children living in suburban and urban areas. The percentage of parents in rural areas with a bachelor's degree or higher were much lower when compared to urban and suburban areas (42). Low health literacy rates were often caused by a lack of education. According to Yin et al., parents with low health literacy faced more of a challenge when making medical decisions for their children (s289). Putting this injury severity score in place to assist doctors when making medical decisions, it would help them give better guidance to parents regarding medical decisions for their children regarding amputations.

Once the pediatric version of the PSI is in place, doctors can use this severity score to relay information to parents in a way that takes into account the strategies suggested by the U.S. Department of Health and Human Services. This would help to improve health literacy and decision-making regarding amputations. Doctors will achieve this by making sure all written information given to parents is not too complex, and keeping an open line of communication between themselves and the parents. Another strategy that could be used is the use of a "universal precaution" approach.

The U.S. Department of Health and Human Services reported that using a "universal precaution" approach from infectious diseases could transfer over to health literacy. When a doctor uses a "universal precaution" approach for infectious diseases they always take the same precautions for every patient, for example always putting on gloves, because they do not know just by looking if a patient has a disease. Applying this to health literacy, the U.S. Department of Health and Human Services contended that if a doctor always assumed that patients would have difficulty understanding medical information and made sure to express information in a simple, easy to understand manner, the issue of health illiteracy would be decreased.

As much as injury severity scores were helpful in determining whether a patient should receive amputation or limb reconstruction, it should be kept in mind that a number cannot always determine a patient's status. There were many factors related to hospitals or health care facilities that these scores did not account for such as the availability of resources or the experi-

ence of the surgeon. While it was very difficult to account for those kinds of factors within the score itself, efforts should be made to improve the score in other ways.

To further improve on parental medical decision-making regarding amputations and the pediatric version of the PSI, a study should be conducted to test the accuracy of the pediatric version of the PSI. This could be done in one of two ways. Scoring current pediatric patients whose parents and doctors are making medical-decisions to either amputate or reconstruct with the pediatric version of the PSI alongside others scores to compare them could yield results as to how to improve the pediatric version of the PSI.

Another way to test the accuracy of the pediatric version of the PSI would be to take pre-existing data from past pediatric patients who have already had limb amputations or reconstructions and score them with the pediatric version of the PSI. This data would aid in testing and finding improvements for the pediatric version of the PSI. These studies could reveal what kind of pediatric specific variables might be needed to improve the accuracy of the pediatric PSI. As stated earlier, there are many differences between adult and pediatric patients. The better tailored the variables of this score are to pediatric patients, the more accurate its recommendations will be.

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