Multiple Amputations: Considerations for Life Care Planning

Carol Hadley Fricks, Lisa Gay, and Caroline Williams
Case In Point Life Care Planning

Abstract

This article will explore the unique challenges that a person with multiple limb amputation faces and provide recommendations for potential items to include in a related life care plan. There have been significant advances in prosthetic technology in the past several years and the tendency is to provide someone with multiple limb amputations with the most advanced dynamic systems such as myoelectric arms for a person with bilateral upper extremity amputation; however, the authors caution that although these technologically advanced systems have their place in life care plans, sometimes body powered systems provide a greater level of functionality and comfort. This article will explore the causes of multiple amputations, types of upper and lower extremity amputations, and the impact the level of disarticulation has on prosthesis use and functional abilities. Furthermore, upper and lower extremity prosthesis options will be reviewed, inclusive of criteria that are considered by the prosthetist when determining the optimum choice, which may include both body-powered and myoelectric/microprocessor prosthetic devices. Innovations in customization will be reviewed. The authors also provide items for consideration for inclusion in a life care plan unique to an evaluee with multiple amputations that will increase independent function as much as possible while acknowledging the potentially significant limitations created by multiple limb loss. Geographical location is also considered as having the potential to impact the needs of the evaluee. Finally, prosthetic costing, frequency, and use of the L-Code HCPCS System will be reviewed.

Introduction

Many amputations are caused by vascular disease and trauma, although cancer and congenital deformities are also less frequent etiologies (Varma et al., 2014). Approximately 7% of individuals with a trauma-associated amputation have multiple limb loss. Bilateral lower extremity amputation is the most common type of amputation related to trauma (64%),

The costs associated with prosthetic systems are always changing. Costs provided in this article are for reference only and should not be used within a life care plan. The authors have no affiliation with any company cited within this article.

with unilateral upper and lower extremity amputations second highest at 21%, bilateral upper limb amputation at 11%, and amputation of three limbs at 4%. Causes of traumatic multiple limb loss include motor vehicle/motorcycle accidents, railway accidents, electrocution, workplace accidents, agricultural accidents with farm equipment, and fireworks/explosives. Interestingly, amputations related to military injuries are not a large category for overall amputations but are a disproportionally large contributor to multiple amputations. According to data from 2014, Operation Iraqi Freedom and Operation New Dawn: 1,648 individuals suffered military-related major limb amputations and nearly 31% of those individuals lost more than one limb (Pasquina et al., 2014).

Although the authors have prepared numerous life care plans for evaluees with multiple limb loss due to traumatic etiology, the primary causes for amputation in life care plans for triple and quad amputations are from a vascular or infectious etiology, particularly sepsis secondary to necrotizing fasciitis, compartment syndrome, or pyelonephritis. Pasquina et al. (2014) noted that

> along with amputations resulting from trauma, many individuals with multiple amputations have endured them as a result of dysvascular disease. Over recent years, amputations as a result of dysvascular disease have risen to comprise more than 80% of new amputations occurring in the United States every year. Those with diabetes comorbid with dysvascular disease make up 74% of those with dysvascular amputations, and these individuals with diabetes comorbid with dysvascular disease have a 55% chance of enduring an amputation of their contralateral limb within 2-3 years of their initial amputation.

Etiology comes into play when determining the probability of interventions being required by the evaluee. For instance, an evaluee with traumatic amputations of multiple limbs will likely require multiple revision surgeries to optimize their residual limbs. There may also be additional issues related to trauma such as fractures, soft tissue damage, peripheral nerve damage, traumatic brain injury and/or post-traumatic stress disorder that need to be considered as well. For an infectious or vascular etiology of multiple limb loss, co-morbidities need to be considered such as diabetes, hypertension, kidney disease and peripheral vascular disease, and an apportionment of future costs may be indicated. Of note, evaluees with vascular compromise are likely to have underlying cardiac disease and may have a decreased tolerance for prosthetic usage as it is estimated that the energy cost of ambulation for individuals with bilateral trans-femoral amputations increases nearly threefold (Pasquina et al., 2014).

Upper Extremity Amputations

Upper extremity amputations account for the majority (68%) of trauma-related amputations (Varma et al., 2014) and include: forequarter, shoulder disarticulation, transhumeral (above elbow), elbow disarticulation, transradial (below elbow), hand/wrist disarticulation, transcarpal and finger amputations. Per Arm Dynamics (2022), body-powered elbow prostheses with myoelectric hands are typically used for individuals with transhumeral, shoulder disarticulation, or forequarter amputations. Myoelectric limbs are typically not well tolerated by evaluees with this level of amputation, largely due to the weight of the prosthetic limb. Body powered prostheses rely on a system of cables or harnesses along with manual controls in many cases, to control the limb itself. The user operates and controls the prosthetic arm using other parts of the body, such as their shoulder, elbow, or chest. The myoelectric-controlled prosthetic arms are externally powered but are not driven by the muscle strength of the evaluee. For individuals with bilateral transhumeral amputations, a prosthetist may prescribe both body-powered and myoelectric prosthetic arms. Some individuals use body-powered prostheses for some activities such as gardening, sports or shoveling snow, and use myoelectric prostheses for work or avocational activities.

In some cases, a prosthetist will not prescribe a myoelectric arm until their patient can demonstrate proficiency with functional use of the body-powered limb. Many individuals still prefer the classic hook hand as they find this device to be more functional. Also, for the more complex myoelectric limbs and hands, there is an increased risk of malfunction and the need for more frequent repairs. Body-powered limbs have the advantages of durability, shorter training time, lighter weight, biofeedback through the cable system, and less frequent need for maintenance; however, they could benefit from improvements in control. Conversely, myoelectric prostheses have been shown to improve cosmesis, offer reduction in harnessing, provide access to effortless strength, and have multiple grip patterns and more natural hand movements, but they tend to be less durable and many of them cannot get wet. There is a prosthesis rejection rate of 30% to 80% with the lowest rejections occurring for transradial prostheses and the highest rejection rate for partial hands, shoulder and transhumeral prostheses. Additionally, 30% to 50% of individuals with amputations do not use a prosthesis regularly and compliant users average a wearing time of 9.5 hours per day (Berry, 2020b).

Options for myoelectric arms and hands include the Hero Arm by Open Bionics, iLimb by Touch Bionics, and a hybrid system that uses a shoulder girdle with a myoelectric ErgoArm Plus elbow and a myoelectric wrist/hand. Disadvantages of these systems include the high device costs, frequency of maintenance including replacing the motor at regular intervals, materials used to construct the limb which can cause skin irritation, inflammation or infection, the level of training required takes longer, and they can be difficult to control. For reference purposes, a myoelectric prosthetic arm with a myoelectric hand can cost approximately \$100,000 - \$120,000, and the cost for the same myoelectric prosthetic system with added Co-Apt system can be 20% to 45% higher. Conversely, a hybrid system built with carbon fiber that utilizes a body powered lockable elbow, a myoelectric wrist, and basic myoelectric hand with an additional split hook costs approximately \$80,000. An example of an alternate, more cost-effective, myoelectric option is the Hero Arm, which costs between \$10,000 and \$20,000 depending on custom features, but with this decreased cost there can also be decreased features and functionality, such as lifting strength, which would need to be taken into consideration.

There have also been significant advances in myoelectric hands which include the Ottobock's MyoHand VariPlus Speed, Greifer hand, Electrohand 2000 for children, Michelangelo hand, and bebionic hand, and Touch Bionics i-Limb Ultra Revolution - an iPhone compatible hand. The Michelangelo hand is one of the most technologically advanced bionic hands available and offers nine different movement patterns. If the evaluee has been determined to be an appropriate candidate for myoelectric arms/hands, consideration should be given to include a back-up body-powered system, as bionic limbs often break down and require frequent maintenance. Additionally, there are other prosthetic arm/hand options which are considered cosmetic-only prostheses and lack functionality, which include full or partial silicone prostheses and the Ottobock MyoSkin Natural cosmetic gloves, which come in a variety of colors and custom skin tones. These cosmetic options can be very beneficial for everyday or situational use by the evaluee, and inclusion of these options should be considered based on the evaluee's individual concerns and goals. Unless the life care planner is also a prosthetist, cost estimates should only be included in the life care plan for the prostheses prescribed by the treating Prosthetist. Life care planners should not go beyond their scope of practice and include costs for prosthetic limbs not currently being used by the evaluee, nor likely to be prescribed in the future. If possible, establishing communication with the treating prosthetist is optimal to obtain information about whether other prosthetic systems are being considered.

Cost estimates for supplies for upper extremity prostheses should be individualized, but costs typically include socks/liners, gloves, and potentially lotions or skin care products. For a body-powered prosthetic limb, supplies may also include a hook to hand cable adapter and hook tension bands. Typical supplies for myoelectric prostheses include replacement batteries and battery charger as well as custom gloves and/or living skin.

Lower Extremity Amputations

Lower extremity amputations include hemipelvectomy, hip disarticulation, transfemoral (above knee), knee disarticulation, transtibial (below knee), ankle disarticulation, Syme, and foot which could include partial foot, transmetatarsal, or numerous toes. Options for prostheses include passive systems, microprocessor knees, patellar-tendon weight bearing (PTB) prostheses, and the Blatchford Aqualimb for showering. The PTB is suitable for 90% of individuals with transtibial amputations. Potential passive knee joints include the mono or polycentric manual-lock weight activated or hydraulic system, or a jointless transtibial prosthesis such as the Ottobock manual lock knee. There are also enhanced composite design passive prosthetic feet including Ottobock's Taleo foot and Terion K2 foot, and Infinite Technologies' BiOM ankle foot. As for the more advanced programmable options, there are microprocessor knees like the Kenevo, Genium X3 and C-Leg 4 knees produced by Ottobock, and microprocessor feet like the Empower and Meridium, also produced by Ottobock.

An important factor in determining which type of prosthetic device is considered reasonable for inclusion in the life care plan is the functional ambulation level (K-level) of the individual with a lower extremity amputation. There are five K-levels as depicted in Table 1.

The ambulation level of the individual will largely influence the type and complexity of the prescribed prosthesis. For example, the Genium x3 was specifically designed for a K4 level ambulator and supports activities such as running, swimming, and ascending stairs step-over-step and would not be an appropriate prosthesis for a K2 or K3 level ambulator. Body weight and habitus are also considered as there are weight limitations to the microprocessor knees. Again, the life care planner is cautioned to not go beyond their scope of practice and include cost estimates for prostheses that have not been prescribed by the treating prosthetist.

Additionally, the K-level of the individual will be important to consider when determining which specialty attachments and which level/type of assistive aids and back-up ambulation options should be included. For an individual with multiple amputations, the requirements dictated by their multiple amputations may outweigh what would be reasonable based on ambulation level alone. For example, it may be more reasonable to include a

Levels	Rehabilitation Potential
K0	Does not have the ability or potential to ambulate safely. (non-prosthetic wearer)
K1	Has the ability or potential to use a prothesis for ambulation on level surfaces. (transfer prosthesis, limited/unlimited household ambulator)
K2	Has the ability or potential to ambulate and successfully navigate low level environmental barriers such as curbs or stairs. (unlimited household ambulator/limited community ambulator)
K3	Has the ability or potential for ambulation and to successfully navigate most environmental barriers with some utilization beyond simple locomotion. (unlimited community ambulator)
K4	has the ability or potential to ambulate exceeding basic ambulation skills with high impact, stress, or energy. (typical child or adult athlete).

Table 1

Functional ambulation level (K-level) of the individual with a lower extremity amputation

manual wheelchair rather than a power wheelchair for a K3/K4 ambulator; however, if that K3/K4 ambulator also has an upper extremity amputation, a power wheelchair may be the more reasonable primary option, with inclusion of a manual wheelchair as a back-up.

Cost estimates for supplies for lower extremity prosthesis should be individualized and typically include liners and socks, which are available in 1, 3 and 5 ply thickness. An evaluee may require varying ply thickness throughout their lifetime and the individual is typically provided with 6 socks which are replaced every 6 months. Additional supplies may include prosthetic salves, chafe barrier cream, Ottobock Derma repair, Adaptskin ointment and/or powders.

Life Care Planning Considerations

Preparing a life care plan for an evaluee with multiple amputations requires additional considerations to maximize the individual's ability to function as independently as possible and to enhance their quality of life. Per Pasquina et al. (2014), the challenges faced by those with single-limb loss are amplified for those with multiple amputations. Pain, lifestyle adjustment, and quality of life return are just a few key areas of concern in this population. Individuals with multiple limb loss are optimally followed and managed by a multi-disciplinary team inclusive of the primary care physician, orthopedic surgeon/plastic surgeon, pain management physician, physiatrist, psychologist/psychiatrist, rehabilitation nurse, prosthetist, physical therapist, occupational therapist, case manager and assistive technology specialist. Additional specialists that may be involved include speech language pathology, recreational therapy, vocational rehabilitation, neuropsychology, certified driver rehabilitation, cardiology, nephrology, and oncology, depending on the individual needs of each evaluee. In general, it is recommended that the multi-disciplinary team be led by a single provider who is designated as the coordinator of information and communication with the evaluee, family members and the multi-disciplinary team. The team coordinator could be the physiatrist or potentially the rehabilitation nurse or case manager/clinical social worker. The advantage of utilizing a case manager as the team coordinator is that in addition to their role as a facilitator of communication to all involved parties, they also have the ability to provide the evaluee and family with information regarding community resources and vendors for equipment and supplies. Also, it is not uncommon for individuals with traumatic etiology for limb loss to have additional injuries which were not initially detected and show up later in the rehabilitative process, such as sprains/strains, traumatic brain injury, or mood disturbance that may be detected by the physical or occupational therapist. Access to support groups and individual counseling will likely be of benefit to address grief, altered body image, and adjustment/coping.

There are numerous things that are taken into consideration when determining which prosthetic system is most appropriate for each individual. These include the level of the amputation/disarticulation, the activity and ambulation level of the individual, their body type and stature, the weight of the prosthetic, and how likely the individual is to use the prosthetic limb. The most critical aspect of prosthetic limb selection is obtaining the optimal fit of the socket. The BOA system is a patented system by Arm Dynamics that is used in body-powered prosthetic limbs and in sports shoes that allows the wearer to tighten or loosen the socket or shoe while wearing it. The BOA system allows for optimization of fit and allows for volume fluctuation. In general, it is recommended that, when possible, the individual with an amputation should work with a limb specific Certified Prosthetist/Orthotist (CPO). For individuals with upper and lower extremity amputations, optimally they should be evaluated by both an upper extremity CPO specialist and a lower extremity CPO specialist with coordination of care.

The key to successful prosthesis use is the ease of independent donning and doffing of the prosthesis which is particularly challenging for individuals with bilateral upper extremity amputations. This usually requires the use of a bilateral harness system using a control suspension or attachment strap that allows the prostheses to be removed in a place/position to be ready for re-donning, such as a wall mounted hook or rack. An individual with mixed upper and lower limb loss will have challenges associated with an absent hand or hands when donning and doffing their lower extremity prosthesis. The attachment of pull-tabs to the lower extremity prosthesis or liner to allow for manipulation with an upper extremity end prosthetic device or an individual's teeth is a simple solution that should be considered (Pasquina et al., 2014).

In general, individuals with bilateral lower extremity amputations should have a properly fitting manual wheelchair as a back-up for times when not wearing their prosthetic legs. For individuals with upper and lower extremity amputations, a combination of manual and power wheelchairs should be included in the life care plan. Home modifications for individuals who are likely to utilize a wheelchair, such as entry and threshold ramps and widened doors and hallways, need to be taken into account, even if the wheelchair is not in daily use. Special seating systems will be required for individuals with hip disarticulation or hemipelvectomy amputations for both optimized positioning and pressure sore prevention. Additionally, when considering alternate ambulation options for those with myoelectric or microprocessor prostheses, it is reasonable to include a well-fitting body-powered or passive prosthetic device as a back-up to be worn for tasks incompatible with the more technology-driven device and during myoelectric/microprocessor maintenance periods.

Additional considerations for life care planning for an evaluee with multiple amputations include pain management/pain control interventions, adaptive clothing and a clothing allowance as use of prosthetic limbs can cause increased wear and tear on clothing, vehicle modifications and training, attendant care, and home maintenance/yard maintenance. Pain management measures that can be considered are TENS units, acupuncture, massage and mirror therapy. Attendant care requirements will likely be increased for individuals with multiple limb loss, with the amount of care determined by the evaluee and treating providers.

Assistive devices/adaptive aids should also be considered, both for use with and without a prosthetic device. Items to consider include a universal cuff which can be used with a residual limb for holding utensils, modified eating utensils (swivel, build up grip, and/or angled), bidets, clamps and suction cups to hold personal grooming items like brushes and toothbrushes, voice activated cell phones and electronic devices, and environmental controls for an individual's home (Johnson, 2011). Additionally, home items and modifications such as an electric hi-low bed like the Flex-A-Bed, a three-in-one lift recliner chair, padded shower chair/bench, door levers instead of knobs, motion- or foot-activated soap dispensers, a full-body air-blower for hands-free drying, and motion-activated lighting can improve safety and quality of life for an individual. An environmental control system such as the Amazon Alexa Smart Home ecosystem, which is a convenience for many of us, is a necessity for someone with multiple limb loss, particularly those with bilateral upper extremity amputations. Smart home technology allows for voice activation of thermostats, virtual assistants, home entertainment, lighting, security systems, cameras, sensors, kitchen appliances, automated vacuums, etc., and is highly recommended for inclusion in the life care plan for an individual with multiple limb loss.

Optimally, life care plans for individuals with multiple limb loss should include prosthetic attachments that allow the individual to resume as many previously enjoyed recreational and sports activities as possible. Companies such as Fillauer TRS Inc. offer numerous options for prosthetic attachments that allow an individual to resume activities such as basketball, volleyball, swimming, paddleboarding/canoeing, field hockey, cycling, baseball, golfing, fishing, shooting, archery, billiards, and downhill skiing. Most of Fillauer's attachments are off the shelf, however, they will work with individuals to design custom attachments for other activities such as high-level competitive lifting. Of note, all their sports attachments are designed for use with only body-powered prosthetic limbs. The company also has a line of pediatric attachments which allow a child to grasp toys and various objects, as well as enable the child to crawl. Optimal function can be acquired with these prosthetic attachments; however, it should be noted that the key to optimization of function is the socket fit which can be fine-tuned with the BOA system for personalized on-the-go adjustment of the socket. For the active individual with bilateral lower extremity amputations, several options exist for carbon fiber running blades such as those from Ossur, Fillauer, and Freedom. Ottobock offers a Pro Carve Sports prosthesis that allows the user to ski or snowboard. Additionally, adjustable heel prosthetics are now available allowing the individual with lower limb amputation(s) to wear heels.

Geographical Considerations

Individuals who reside in remote areas such as the US Territories (Puerto Rico, US Virgin Islands, Guam, etc.) may not have access to a local prosthetist and therefore would likely need to travel for their initial prosthesis selection and fitting, and then need to send their prosthesis to the States for maintenance and repairs. In these situations, it would be reasonable to include a back-up prosthetic limb, particularly for someone who wears their prosthetic limb(s) on a daily basis at work. The heat and humidity experienced in island communities causes items such as prosthetic limbs to be more susceptible to mold and degradation. Evaluees in these climates may require more frequent replacement of parts or prostheses and use of their old prosthesis for back-up is not ideal. Also, for evaluees who have to travel to their prosthetist, cost estimates should be included for this expense and, if appropriate, additional costs for hotel expenses and a rental car. Evaluees living in remote or rural communities in the mainland United States may also incur travel expenses to see their specialist and/or prosthetist that should be included in the life care plan. Additionally, individuals living in areas such as the Midwest and northern states, cost estimates should be included for snow removal services. Replacement costs of housecleaning, home maintenance and yard/lawn maintenance are also typically required for an individual with multiple limb loss.

Prosthetic Costing

Costing for prosthetic devices is based on the Medicare L-Code Healthcare Common Procedure Coding System (HCPCS), such that each component can be identified by a four-digit L-Code which can be used to determine the associated Medicare reimbursement rate. Medicare reimbursement rates can be found in the Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS) list available through the Centers for Medicare and Medicaid Services website (CMS.gov). When costing for the purposes of the life care plan, two important things need to be considered. First, the Medicare contracted reimbursement rate does not equate to the fair market value or usual, customary and reasonable (UCR) rate that is billed by medical providers. According to an article by Berry (2020a), the UCR rate for prosthetic devices and parts is usually set between 20% to 30% above the Medicare pricing point with an average rate nationally of about 26.5% above the Medicare rate. Second, the geographic region can impact the Medicare reimbursement rate, and costs should be calculated for the evaluee's specific geographic region using the state/territory specific reimbursement rate or nationally using the average reimbursement rate. It may be useful to know that the geographically specific UCR rates for many L-Codes can also be found through many costing databases like Find-A-Code and Context4 Healthcare.

In addition to the prosthetic device cost, costs will also be necessary for prosthetic supplies. Each evaluee will likely require standard supplies such as socks and liners and possibly skin care items, as well as additional supplies that are chosen to meet their individualized needs, concerns and goals, like the previously mentioned cosmetic covers. It is important to note, that regardless of the supplies being included, the cost of supplies is not relational to the cost of the prosthesis being utilized. The supplies have designated costs, and therefore, the costs for supplies should be calculated based on the cost of each item. As a result, the costs for standard supplies should be fairly consistent across life care plans.

Another factor affecting costs within the life care plan is replacement frequency. When determining replacement frequency, it is important to consider where the evaluee falls in their prosthetic progression. For the first 24 to 36 months following amputation the residual limb is still healing and changing, resulting in substantial changes to the prosthesis and more frequent socket replacement. During this period, socket replacement frequency may be as frequent as every four to six months, while long-term socket replacement frequency is closer to once every two to three years. Additionally, the primary goal post-amputation is to get the individual up and ambulating, therefore, it is common for the individual to be fitted with a preliminary simple prosthesis. This would be replaced with subsequent progressive prostheses as their abilities improve until they reach the training and ambulation capabilities compatible with their optimal prosthetic device end point. During the initial 24 to 36 months, the individual may go through several device replacements/upgrades at an increased frequency; however, after this period, the long-term reasonable useful life of an adult prosthesis corresponds to a replacement frequency of once every five years. The typical replacement frequency for pediatric prostheses is every 12 to 18 months to accommodate for the child's rapid growth.

For multiple amputations, it is important to consider the necessary training and progression for each device and how multiple amputations may influence this timeline for each individual device. For bilateral upper extremity amputation, training should begin with the prosthesis used on the longer residual limb, which is likely to be the dominant arm or hand. The prosthetic training process will be repeated on the non-dominant side once competency is achieved. Lastly, training is continued with the individual performing their daily tasks wearing both upper extremity prostheses (Johnson, 2011). Individuals with mixed upper and lower limb loss may utilize an upper extremity crutch prosthesis when beginning their standing and ambulation training with their lower extremity prosthesis (Pasquina et al., 2014).

Medical bills are sometimes considered regarding costs and replacement frequencies; however, because of the progressive nature of the initial post-amputation stages, past medical bills may not accurately reflect the long-term needs of the individual with regards to the specific prosthetic device and replacement frequency. Another reason past medical bills may not be a reliable source for costs is the limitations set by the individual's insurance benefits coverage. It is possible for an evaluee to have a current prosthetic device that is suboptimal for their functional goals due to device cost restrictions based on their benefits coverage, or even the etiology of their amputation. For example, Aetna's policy specifies that a microprocessor leg prosthesis will be provided for K3 or above functional level individuals with knee disarticulation or transfemoral amputation "from a non-vascular cause (usually trauma or tumor)" (Aetna Clinical Policy Bulletin, 2022). When constructing the life care plan, it is important to include the most optimal prosthetic device, as recommended by a prosthetist, to meet the evaluee's goals, rather than allowing past medical bills to dictate which device is included.

Conclusions

Creating a life care plan for an evaluee with multiple limb loss requires much more than the sum cost of each limb's prosthetic device or system. Individualization is required for the type and level of each amputation, the preexisting capabilities of the evaluee, and the activities they wish to perform. Comorbidities – both those which were preexisting and those which developed in relation to the amputation or traumatic etiology, geographic location, and the wishes and goals of the evaluee should be considered. A multi-disciplinary team, which incorporates numerous physicians, therapists, nurses, and specialized prosthetists, is required and the visits and therapy schedules will likely be prolonged in order to focus on proper care and training related to each amputation site. A life care planner should consider the need for back-up prosthetic devices and wheelchairs, devices and attachments for specialized activities, supply needs, maintenance requirements, and the cost of each prosthetic system. Customization of the environment and adaptive aids for an individual with multiple limb loss will be crucial to helping them achieve the highest possible level of function and quality of life. The authors did not include a discussion on the life care planning considerations for a child, young adult, or geriatric evaluee with multiple limb loss as this would likely require separate articles.

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