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Title

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Permalink

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Journal

BMJ Supportive & Palliative Care, 14(e3)

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Publication Date

2024-12-19

DOI

10.1136/spcare-2023-004439

Peer reviewed



HHS Public Access

Author manuscript

BMJ Support Palliat Care. Author manuscript; available in PMC 2025 January 15.

Published in final edited form as:

BMJ Support Palliat Care. ; 14(e3): e2302–e2315. doi:10.1136/spcare-2023-004439.

Personal legacy and treatment choices for serious illness: a scoping review

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Abstract

Background—Legacy – how one hopes to be remembered after death — is an unexplored and important dimension of decision-making for people facing serious illness.

Objectives—We conducted a scoping review to answer the following research questions: 1) How do people making treatment choices conceive of legacy? and 2) What treatment choices do people make with legacy in mind?

Eligibility criteria—Participants included people facing serious illness who discussed how they wanted to be remembered after their own death, or how they hoped to impact others, as they made treatment choices. Studies in English published between 1990–2022 were included.

Sources of evidence—We conducted searches in electronic databases including Medline/ PubMed, CINAHL, PsycInfo, SocialWork, AnthropologyPlus, Web of Science, ProQuest and EMBASE databases.

Data synthesis—We used an electronic screening tool to screen abstracts and review full text articles suitable for inclusion. We analyzed included articles using Atlas.ti. We constructed tables and narratively synthesized the findings.

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AUTHOR CONTRIBUTION

Marlaine Figueroa Gray and Sarah Randall conducted the scoping review, including abstract screening, full text review, and extraction of data from included studies; Nora Henrikson and Mateo Banejas provided mentorship all aspects of the scoping review process. Nora Henrikson and Marlaine Figueroa Gray created extraction tables and evidence maps characterizing the data. Marlaine Figueroa Gray wrote analytic memos and all drafts of the paper. Sarah Randall and Nora Henrikson reviewed these tables for accuracy and provided feedback. Nora Henrikson and Gery Ryan reviewed and gave feedback on multiple analytic drafts. All authors reviewed and gave feedback on the final version of the paper.

Results—We identified three major intersecting legacy goals that influence choices people facing serious illness make about their treatment and health behaviors, and the types of choices people make with legacy in mind. The three legacy goals are: remembrance of the individual self, remembrance of the social self, and impact on others' well-being.

Conclusions—We identify the importance of legacy to patient treatment choices. Understanding for whom this construct is important, what types of legacy goals people hold, and how those goals impact treatment choices is necessary to provide patient-centered whole-person care to people facing serious illness.

Keywords

Legacy; treatment choices; serious illness; remembrance; impact; personhood; values

BACKGROUND

Legacy – how one hopes to be remembered and how one impacts others after death — is an unexplored and important dimension of decision-making for people with serious illness. A growing body of evidence is exploring the impact of legacy creation in the context of illness and health care and demonstrates that interventions that support legacy creation improve quality of life, enhance one's sense of dignity, reduce psychological distress, support one's spirituality, and improve social relationships (1, 2, 3, 4, 5, 6, 7). Articulating one's values and legacy goals may also provide clarity regarding the treatment choices that would support them, with the potential to optimize current care, facilitate goals of care conversations, reduce decisional regret, alleviate provider moral distress, and mitigate treatment-related grief of loved ones (1, 7, 8, 9).

People may first encounter the construct of legacy when they reflect on the legacy of others, for example by remembering grandparents who have died. As life progresses, the significance and proximity of one's own legacy gradually increases, becoming most pronounced in advanced age (10). However, life events can speed or force engagement with one's own legacy (e.g. a health scare; serious illness diagnosis; family planning; birth or death of loved ones; option to become an organ donor). In such cases it may not be one's age, but one's perceived or actual proximity to the end of one's life that sharpens the focus on one's legacy (11). The dying process itself has been theorized as a distinct stage in the human life cycle with specific associated tasks – a critical task being legacy creation (1, 12, 13, 14, 15). Though people may work to achieve legacy-related goals at any timepoint during an illness, the activities associated with legacy creation, when supported by health care, are often incorporated into end-of-life care or palliative care (3, 16, 17, 18, 19).

Considering one's legacy can help people living with serious illness adapt to facing their mortality and to clarify their values and goals (20). Legacy planning may happen concurrently with decisions about one's medical care, and studies suggest that the two are linked (6, 21, 22). The extant literature on personal legacy in the context of health care typically examines interventions that might include the creation of a legacy document, such as dignity therapy or life review (1, 12). Research regarding supporting the care preferences of people facing serious illness often examine patient-provider communication and discuss

how various documents that express treatment preferences, such as advance directives or Physician Orders for Life-Sustaining Treatment (POLST), can be created and used (23). Many interventions offered at the end of life, including those discussed in the POLST (24) – resuscitation, mechanical ventilation, medically assisted nutrition and hydration – involve aggressive care within a hospital setting. These procedures often cause distress to the people undergoing them, as well as to providers and loved ones caring for them, and negatively impact the quality of the dying experience (25). Providing end-of-life care consistent with patient preferences remains a challenge (26).

Furthermore, how patients define legacy, what it means to them, and how that meaning informs medical decisions, is not well understood. There are studies that describe the importance of legacy to people facing serious illness, but relatively few that provide a definition of legacy, with Hunter (11), Von Post (27), and Boles (28, 29) providing the most comprehensive. We conducted a manual preliminary literature scan in PubMed to identify existing reviews and primary studies potentially relevant to our topic. Our preliminary scan suggested that patients facing serious illness such as cancer consider legacy when making medical decisions, for example forgoing expensive treatment with limited or unknown clinical benefit to preserve one's inheritance for their children (30, 31). Yet, very little is known about the role of legacy in treatment decisions of patients across the continuum of serious illness, from receiving genetic test results that indicate a predisposition to serious illness, to receiving a life-limiting diagnosis, to choosing treatment options to end-of-life care (32, 33). In particular, no comprehensive conceptual model exists that would provide understanding of how legacy is considered by people facing serious illness making health care choices.

People making treatment choices often do so with legacy in mind, but there are no studies that explore the connection between legacy goals and treatment choices. After completing a preliminary literature review and analyzing prior research (34, 35, 36), we described legacy as being composed of three distinct types: primary, secondary, and tertiary. Primary legacy comprises a living individual's intentions about how they wish to be remembered after death, and the impact they have on others (6, 21, 22). We define secondary legacy to mean how others remember a deceased person known to them after their death, including bereavement and memorialization activities (34, 35, 36, 37). We conceptualize tertiary legacy as the recognition of the legacy of international, national (38), political (39), or professional impact (40) of a person not immediately known to those who memorialize them. There has been a significant amount of research on secondary legacy and bereavement outcomes in the context of health care (41, 42, 43). However, little research has been done on how primary legacy influences an individual's health care choices. We conducted a scoping review to examine the conceptual foundations of primary legacy, and how these conceptions impact health care choices.

Objectives

The objective of this scoping review was to inform a conceptual framework of primary legacy and patient treatment choices by understanding the extent and type of academic discourse addressing the concept of legacy by people facing serious illness. We examined

primary legacy as it relates to medical decision-making, excluding literature discussing secondary legacy. Our scoping review was designed to answer the following research questions: 1) How do people making treatment choices conceive of legacy? And 2) What treatment choices do people make with legacy in mind?

METHODS

Protocol and registration

The protocol for this scoping review has been published elsewhere (44). This scoping review followed the guidelines put forth by Levac et al. (45), which expands the framework introduced by Arksey and O'Malley (46), as well as the Joanna Briggs Institute Reviewer's manual (47). This review followed the Population, Concept, Context framework put forth by the Joanna Briggs Institute (48, 49). The results are reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Review guidelines (PRISMA-ScR) (see Figure 1) (50).

In conducting this scoping review, we acknowledge that our prior experiences and personal and professional backgrounds may have influenced our search strategy, data extraction, and synthesis of the findings. Each author has had lived experience supporting family members at the end of life, and two authors experienced the death of a close family member during this study. These experiences may have shaped our sensitivity to the importance of legacy considerations for people making treatment choices at the end of life. To minimize potential bias, we followed a rigorous and transparent methodology, including writing a detailed reflexivity statement before beginning the review, and developing an iterative process of team discussion and consultation with external experts, including subject matter expert librarians.

Eligibility criteria

Table 1 summarizes our inclusion criteria.

The population investigated included people facing serious illness. Articles of interest discussed, directly or indirectly, primary legacy—how people want to be remembered after their own death, or how they impact others—as they make treatment choices. We also included articles that discussed health behaviors if they were highly relevant to the concept of legacy. Because end of life is both a time during which people consider their legacy and during which they are making multiple high-stakes choices about medical treatment, we paid close attention to how participants described their dying process or death itself as legacy. We excluded articles not related to illness, medical care, or health behaviors, and excluded articles discussing legacy of another person (i.e., secondary legacy). We excluded choices made in a health care context that were about legacy but did not influence one's treatment or health (i.e., body donation, organ donation). We excluded articles in which the concept of legacy was discussed separately from treatment choices. We excluded intervention studies unless they included a rich qualitative component addressing legacy concepts. Any contextual setting was eligible for inclusion (49). It was out of scope for us to look at people who were not facing serious illness; however we understand that

relatively healthy people also consider legacy when making choices about fertility, living organ donation (51), etc.

Sources of evidence

Since our preliminary literature review confirmed that the concept of legacy is discussed across multiple disciplines, we included a variety of relevant literature databases. We explored the following electronic databases that we chose in consult with a subject matter expert librarian: Medline/PubMed, CINAHL, PsycInfo, SocialWork, AnthropologyPlus, Web of Science, ProQuest and EMBASE databases. We also hand-searched the grey literature to identify highly relevant sources. Grey literature sources include 4 dissertations (accessed via ProQuest) and 2 letters to the editor. In total, our searches cover the Jan 1 1990 to February 25 2022. The literature search was conducted on February 25, 2022 in English-language literature from 1990 with selected keywords to identify relevant articles and refine the search strategy. We have limited this time window to reflect the advent of legacy research and legacy-oriented interventions in health care settings (28). Translation of non-English language articles was not feasible for this review. After the search strategy was finalized, we conducted our search. While writing this manuscript, we actively surveilled the literature for articles relevant to our topic. We conducted a bridge search before publication.

Search string

The PubMed search string is as follows:

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((“legacy”[TW] OR “legacy making”[TW] OR “legacy-making”[TW] OR “legacy building”[TW] OR “legacy-building”[TW] OR “legacy activities”[TW] OR “dignity therapy”[TW] OR “hear my voice”[TW] OR “life review”[TW] OR “continuing bonds”) AND (“illness”[TW] OR “palliative care”[TW] OR “end of life”[TW] OR “end-of-life”[TW] OR “decision making”[TW] OR “decision-making”[TW] OR (“Decision Making”[Mesh:NoExp] OR “Decision Making, Shared”[Mesh] OR “treatment choices”[TW] OR “values”[TW] OR “mortality”[TW] OR “death”[TW] OR “personhood”[TW] OR “Wills”[Mesh] OR “Advance Directives”[Mesh] OR “Advance Care Planning”[Mesh] OR “Terminal Care”[Mesh]))
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Study selection

We undertook a two-part study selection process. In the first step, two independent reviewers used an electronic abstract screening tool (COVIDENCE) for abstract and full text review to assess the eligibility of each article based on pre-determined exclusion/inclusion criteria. Discrepancies regarding eligibility were resolved by consensus or consultation with a third team member.

After completing the abstract review, two team members (MFG and SR) independently reviewed the full text of all remaining articles using the same dual approach, noting reasons for exclusion. We also examined the reference lists of highly relevant papers and hand searched the grey literature for potentially relevant articles.

Data synthesis

One team member extracted relevant data from each included article and a second team member reviewed the extraction chart for accuracy. Data extracted included study characteristics, populations, study design and setting, data collection methods, and relevant results.

To map the current evidence and identify both patterns and gaps across the body of evidence, we developed an evidence map table. To synthesize the findings across studies, we analyzed included articles using Atlas.ti, which has been successfully used in systematic reviews to identify relevant themes, definitions, and concepts (52). We coded all articles, using our charting elements (Table 2) as a priori codes. We added emergent codes as needed that illuminated the concept of legacy and its role in treatment choices. We identified elements of legacy goals important to participants in included studies as they made treatment choices and synthesized our findings in coding memos which were discussed with the team, and which inform our results.

RESULTS

In total, 21 studies including 609 participants met inclusion criteria. Fifteen of the included studies were conducted in the United States. Other study locations included the United Kingdom (2 studies), Singapore (2 studies), Canada (1 study), and Israel (1 study). Most (19 studies) were qualitative studies using semi-structured interview data collection and analysis techniques. Two studies were not empiric studies: one commentary providing personal reflections and one single case report. Most commonly, qualitative data were collected cross-sectionally at a single point in time (15 studies); four studies included multiple interviews longitudinally over time. Five studies were conducted alongside or as part of intervention studies. Interventions included advanced care planning; family dignity therapy; dream interpretation; and elicitation of goals of care. Of the qualitative studies that reported a theoretical approach, 6 used a phenomenological approach, 2 used a grounded theory approach, and 1 used a narrative theory framework.

Per inclusion criteria, all studies included adults. Most study participants were older adults. Reported ages ranged from 27–95. Specific illnesses were not commonly reported; where reported, cancer was the most common condition. Most or all participants in four studies included people in hospice settings. Settings for data collection included hospice facilities; cancer centers; hospital or clinic settings; or community organizations, typically those related to hospice, palliative care, or illness-specific support organizations (e.g. cancer). For studies conducted in the U.S., populations were mostly non-Hispanic White. Most studies were published after 2005 (Table 3).

Defining legacy

A precise understanding of legacy, its definition, and component parts, is critical to studying how legacy and treatment choices are connected. Though all included articles used the term legacy, a majority of included articles did not provide a definition of legacy. Twelve studies included some text explaining the concept of legacy, but only 6 studies provided

an explicit definition (11, 20, 56, 62, 65, 69). All definitions were provided by authors, many citing other authors, and none included patients' definitions of legacy. When legacy was defined, it was most often defined as a process (e.g. specific actions taken to create objects, experiences, or memories that could remain after death), a wish (e.g. the desire to leave something behind after death or influence others' memories) or, less often, as a material object (e.g. the set of items left behind). In some studies, authors did not define legacy per se but created typologies of its component parts (e.g. material, social, biological) (11). Several studies noted that legacy is a multifaceted cultural construct (56, 65) that encompasses personal values and the existential meaning of one's life, beyond one's estate or material belongings (11, 59). Wyman and each of Hunter's three included articles provide definitions of legacy which include biological or genetic dimensions (11, 55, 56, 69). Four articles discussed patient goals and goal-oriented care, and explicitly discussed "leaving a legacy" as a participant goal (55, 62, 65, 69).

Synthesizing the body of evidence, we understand the construct of legacy to include its definition, legacy goals, the act of legacy creation, legacy objects, and the desired impact of one's legacy (Table 4). We define legacy goals as actions people wish to take to influence how they are remembered and how they are able to impact others. We define legacy creation as the process people undertake to meet their legacy goals or create legacy artifacts. We define a legacy artifact as the result of legacy creation work. An artifact may be tangible, such as an autobiography, legal will, or genetic data, or intangible such as one's oral history, stories, examples, or imparted values. We define legacy impact as a person's desired effect that legacy creation and legacy products will have either on one's own legacy or on others.

Legacy goals

We categorized the components of legacy goals of people facing serious illness as: 1) the remembrance of one's self; 2) the continuation or remembrance of one's social role; and 3) impacting the well-being of others (Figure 2). The legacy of one's self includes the remembrance, celebration, or continuation of one's individual identity – one's personal characteristics, values, and actions. The remembrance or continuation of one's social role includes a person's role(s) in their family, in their cultural and spiritual communities, and their professional role. Impacting the well-being of others includes impacting the emotions, behaviors, knowledge, lineage and resources or environment of others who are both known and unknown to the participant. Known others are people personally known to the participant, such as loved ones, other patients, and health care providers; unknown others are those a participant imagines will be impacted but doesn't know, such as future generations of one's family or community, future people affected by a similar illness, or others.

Participants' legacy goals were more expansive than those defined by authors of included studies. In studies in which authors provided definitions of legacy, most were limited to continuation of personal and social identity (20, 59, 61, 62, 63, 65, 68). Some studies also included impacting the well-being of others (11, 55, 56, 69, 71). When individuals discussed making treatment choices that supported legacy goals, they spoke about holding all three goals. Table 5 contains exemplar quotations that illustrate each of these goals via

participant voices. Though we list three discrete legacy goals for the purposes of defining the construct of legacy, participants often hold multiple goals simultaneously, and together the three elements make up the concept of legacy that influences patient treatment choices.

Legacy goals and treatment choices

We identified several treatment choices made with legacy in mind. People facing serious illness thought about legacy when making choices about curative treatment – whether to begin curative treatment, continue, minimize, or discontinue it. Some participants made choices about whether and how to engage in fertility preservation and family building. Almost all studies included examples of people making choices to lower the side effect or symptom burden of their treatment or illness to meet their legacy goals. Similarly, a majority of included studies described treatment choices related to end-of-life care, such as engaging in advance care planning, completing a health care directive, enrolling in hospice, and making choices about location and manner of death. Some included studies discussed choices made related to health, such as modifying health behaviors or participating in some types of health research, including qualitative studies and genetic research. Although the broad domains of people’s choices (i.e., treatment choices, fertility planning, end-of-life care) were similar, the reasoning behind their choices varied. Table 6 depicts the connection between the identified treatment choices and legacy goals. The columns which contain an ‘x’ indicate that the treatment choice was made with the corresponding legacy goal in mind. We discuss these connections in detail next.

Remembrance of one’s self—People in 7 included studies shared legacy goals related to preserving the memory of their **personal characteristics**, including being strong, autonomous, healthy, having a particular skill or being a person of faith, or for simply being themselves (62, 66, 69). To support the remembrance of themselves as a strong person, some participants made the choice to pursue curative treatment (69, 70), while others holding the same goal made the choice to lower side effect burden (66). To support the remembrance of one’s special skills or attributes, some people chose to modify health behaviors to be able to better demonstrate those skills (61, 71). Participating in qualitative health research was also described as a way to support the memory of one’s self though sharing one’s story (62). People made choices about end-of-life care to be remembered as upholding their faith (59).

A majority of studies included participants who described making treatment choices that would impact the memory of their **values**, namely family and religious values. Several people made choices about curative treatment (55, 61, 70), health behaviors (63) or research participation (53) that they felt would demonstrate their deep consideration of family. Some people made choices about fertility preservation and family building that reflected family values (54, 57), and other participants described making choices to lower side effect or symptom burden to demonstrate family values (62, 71). Many people made choices about end of life care that considered family (60, 70), supported their religious values (59, 64) or other core values (20).

Participants in over half of the included studies also made choices that would support being remembered for their **actions** that reflected who they were. They described choosing

curative treatment to be remembered as a fighter (70) or as someone who complied with recommended care (61). Others prioritized lowering side effect or symptom burden to travel to make memories with family (71), to make amends with family (68), or to be remembered for being active (60, 62). Choices about end-of-life care included entering hospice to be supported in transmitting their stories (59, 67), be present with loved ones (64), or consciously model how to face one's mortality (59, 70).

Remembrance of one's social role—Fulfilling one's **familial role** can include choices aligned with socio-cultural expectations of what it means to be “a good parent” (61) or “good daughter” (70) or a good ancestor (53, 61). Supporting the remembrance or continuation of one's familial role was a key goal for study participants that influenced *all* identified treatment choices. Some examples include making choices about curative treatment to be able to pass down one's family story (61), or to teach children how to approach mortality (70). Some participants spoke of participating in health research as a means to benefit one's children, grandchildren and future generations (53). Other participants described engaging in health behaviors in the context of their community identities, describing the importance of tradition, generational continuity and ancestry (63).

Some people held legacy goals that included honoring and preserving **community roles** (59, 63). For these participants, choices about their health behaviors, such as whether and what to eat, and whether to pursue potentially controversial medical options, such as medical aid in dying, were made in accordance with their roles in their religious and cultural communities.

Several participants discussed making treatment choices that would support the legacy of their **professional role**. Some wanted to embark on new professional projects, such as acquiring an advanced degree to teach and impart specialized knowledge they had gained (55), while others wanted to complete projects that were in-process (20, 62). To support these goals, they made choices to optimize symptom management and of end-of-life care.

Impact the well-being of others—Legacy goals of people in nearly all (18) studies included impacting the well-being of others, such as family, other patients, health care providers, and others who will come after. Participants described wanting to support and protect the **emotional well-being** of others, and provided instruction regarding how to face death. To this end, people made choices about their cancer treatment (70), their advance care preferences (58), and their preferences about location of death (i.e., at home, in a hospital) (67).

Several studies described examples of people making treatment choices to influence the health **behaviors** of others living with chronic conditions such as diabetes and heart disease, though the link was strongest for people living with cancer (56). These participants hoped that their experience with cancer and cancer treatment would both educate their friends and families about the disease and influence their health behaviors around preventive screening and healthy lifestyles (55, 56).

Other participants explicitly hoped to increase others' **knowledge**, including making treatment choices that provided learning opportunities for one's family, friends, or care

providers. Three articles included examples of people participating in health research as part of a legacy of helping others, including family and future patients like themselves, by contributing to scientific knowledge and efforts to find a cure so that others may have a better life (53, 62, 64). Some participants spoke of the importance of stewardship of future generations, and their desire to pass on their professional knowledge (55). One article described how participants regarded research participation as a way to be remembered by the research team, an example of both continuing one's personal identity and impacting others (62).

Impacting one's **lineage** refers to the continuation or disruption of one's biological and genetic legacy, as well as one's impact on future generations. Three included articles discussed legacy as the continuation or disruption of biological and genetic lineage. Patients reported choices about fertility preservation and family planning to continue their lineage by making choices about having biological children (54, 57). Haddow provided an example of how people chose to participate in health research as a way to disrupt one's genetic lineage if one belonged to a family with inherited diseases (53).

Many participants held the legacy goal of impacting others' **resources and environment**. Several studies included examples of making treatment choices to support the financial well-being of others, such as pursuing symptom management to allow time to accomplish financial goals, or discontinuing treatment to alleviate financial burden on family or others (55, 58, 62). Participants with dependents were especially concerned with providing continued financial support, and made treatment choices that influenced what they would be able to leave behind for their dependents (62).

Legacy goals related to the act of dying

Participants in the included studies reported choices about the dying process that were concordant with all three legacy goals: the remembrance of one's self, one's social role, and one's impact on the well-being of others. Seven studies discussed how participants approached the act of dying itself as part of their legacy. Some participants made choices about the manner of their death to support the remembrance of the self and their social roles (59, 70). Others made advance care plans or chose the location of their death to support family well-being (58, 60, 67). Others expressed the hope that the way they lived with, and died from, their illness would serve as their legacy, and that this legacy would be of positive benefit to family and others (11, 20, 59, 70).

Tensions regarding legacy considerations during serious illness

There are a series of tensions inherent in supporting legacy goals in the face of serious illness. An initial tension exists between supporting one's agency to achieve legacy goals and the functional challenges of serious illness. As people in our studies became increasingly ill, legacy goals took on a heightened importance. Yet as they experienced decreasing capacity and stamina, they were less able to act as independent agents to achieve their legacy goals (62, 68). For example, several people enrolled in hospice care with the hope that they would be supported in fulfilling their legacy goals, but they were often too sick to enact them (62, 67).

Another tension we noted is that legacy goals may be in conflict with other personal or cultural values, and legacy work may require constant adjustment in relation to one's personal and cultural values. For example, Leichtentritt notes that for many Jewish elders living in Israel, considering medical aid in dying (MAID), even if it was something they were interested in, was, for some, in conflict with their sense of duty to their families, religion and culture, while others felt that MAID supported their personal, religious and cultural values (59). Similarly, several studies noted that discussing legacy is often associated with end-of-life, and conversations about end-of-life or death can be distressing to some families, especially in communities with different beliefs about death than those represented in the predominantly white biomedical model of care (58).

Lastly, the concept of legacy may be fraught for younger people facing serious illness. People who are confronted with serious illness during their younger years, while they are building their families and careers, may feel conflicted about being unable to realize their legacy goals because they are in the beginning or middle of life. At least one study described the difficulty younger patients might have in fulfilling legacy goals, especially if they feel like their lives were "unfinished" (61). The approach to fulfilling legacy goals and the urgency of those goals were different in this vulnerable population.

DISCUSSION

This scoping review synthesized empirical and grey literature exploring connections between patient legacy goals and treatment choices. Our analysis examined what legacy goals mattered most to people living with serious illness, and what treatment choices people made with legacy in mind. This study confirms that legacy is a broad, complex, and potentially universally important human construct influenced by one's sociocultural context (11, 59, 60, 61). Each article included in this review presented examples of how people living with serious illness considered their legacy as they made decisions about treatment options and health behaviors.

In the included studies, people living with serious illness expressed legacy goals that can be conceptualized as efforts to preserve others' memory of one's self, to continue one's social role, and to impact others' well-being. The studies demonstrate that these domains are important to people facing serious illness as they make treatment choices. This is an encouraging finding, since none of the included studies' objectives were to highlight the connections between treatment choices and legacy goals.

We found that the desire and effort to fulfill legacy goals appeared to inform care choices, including choices about curative treatment, health behaviors, preserving fertility and family planning, participating in health research, lowering side effect or symptom burden, and end-of-life care. We know that people facing serious illness work to balance quality of life with length of life (72, 73), and articles often discuss these as end goals. We show that when making choices about possible treatments, people living with serious illness balance treatments that offer a chance to maximize time or augment capacity to allow them to achieve their legacy goals. Similarly, they make trade-offs between legacy goals and medical goals that would negatively impact capacity and time.

Current guidelines for person-centered care include optimizing quality of life (61), but quality of life goals are focused on the present and are often concerned with maximizing comfort in the moment. For example, supporting quality of life frequently means providing pain relief, symptom management, etc. Yet people hold multidimensional goals and make choices that impact their living and dying experience in the present, before death, and how they will be remembered after death. People facing serious illness need time to realize their legacy goals and the capacity to enact them. Thus, they may choose treatments that help them maximize their time, such as pursuing aggressive curative treatment, or augment their capacity, such as optimizing symptom management and modifying health behaviors. These two objectives often come into conflict, and people may make trade-offs between treatments that may seem to extend time and those that will support their ability to enact their legacy goals.

When legacy goals are not elicited or known to health care teams, there are missed opportunities to understand what is most important to people and to provide person-centered care. In fact, some types of care may even negatively impact legacy goals (58, 62, 66). However, legacy goals are not currently elicited in goals of care conversations (74, 75), and may be poorly understood as such by clinicians. Understanding legacy goals are an emerging quality indicator of patient-centered care (62, 76).

Consistent with other studies highlighting the connection between values and treatment goals (65, 72, 77, 78), our study shows that people make care choices with legacy goals clearly in mind and talk about this connection explicitly. Further, we demonstrate that legacy goals are especially salient for people facing mortality or making choices about end-of-life care. Person-centered care involves attending to the whole person, and understanding peoples' legacy goals could help clinicians understand what is most important to their patients as they engage in collaborative decision-making (62, 79).

Despite a growing discussion of the importance of legacy for patients facing serious illness (7, 28, 80), this is still a nascent area of inquiry within health research and health care. It is worth noting that even in a scoping review of studies not intended to address our research question directly, many articles we screened discussed personal legacy in the context of health and health care. We found explicit connections between legacy and treatment choices in 20 studies. Research is needed to understand for whom legacy goals are most relevant, the acceptability of discussing legacy in a health care context, and when and how legacy goals should be elicited. Research is also needed that will examine what structural and social barriers exist for those who wish to but are unable to reflect upon or enact their legacy goals (81). There is also a need for future studies to understand how people in relative good health engage with legacy and make treatment choices.

Patients are the generators of their own legacy goals and are the ultimate decision maker of treatment choices. However, patient voices regarding legacy goals and legacy definitions were relatively underrepresented in this review. No studies put forward patient definitions of legacy, and few studies explicitly described patients' legacy goals or how patients make legacy concordant treatment choices. Yet it was clear that people considered legacy and sometimes prioritized legacy goals above clinical goals. More research is needed to

understand how people conceptualize and act upon the construct of legacy in the health care context.

Additionally, further study is needed to understand the impact of eliciting legacy goals on treatment choices and care outcomes—do people make choices that result in less care, and less intensive care, especially at the end of life? What does legacy-supportive care look like? Does it facilitate a positive dying experience and a good death? Many end-of-life care experiences involve aggressive care that causes unmanageable pain, use of intensive and high-cost equipment and resources, without significant benefit to the patient, and such care often causes moral distress to the providers administering it. Does providing legacy supportive care reduce provider moral distress? Caring for the seriously ill often involves choices about treatments that require trade-offs that are distressing to caregivers, and that they later mourn as inconsistent with what their person “would have wanted.” Can eliciting legacy goals, and providing direction on what type of care would be concordant with their person’s legacy goals reduce caregiver distress, and improve rates of complicated bereavement? This study provides the conceptual foundation for future work to examine the opportunities that eliciting legacy goals has for impacting patient-centered care that supports patient values, and the life goals that matter most to them.

We note some limitations to our review. Since the included studies were largely not intended to address our research question directly, it is possible that more explicit links between legacy and treatment choice existed than our analysis could detect. This scoping review was limited to English-language articles published from 1990–2022. As such we were not able to assess the literature base in other languages. However, we included seminal or highly relevant articles identified through hand searching and prioritized inclusion of research with participants who are non-English speakers.

This scoping review attempted to include diverse perspectives on legacy and included several articles from non-Western countries. However, our sample was predominantly from Western industrialized nations. Future work should seek to understand and incorporate conceptions of legacy from various worldviews, as this construct is embedded in culture.

CONCLUSION

This review identifies the limited empirical understanding of the construct of legacy, and its importance to people facing serious illness as they make choices about their treatment. This study demonstrates that legacy goals are directly linked to treatment choices and the ability to enact values-concordant person-centered care. Attending to legacy goals helps patients navigate the trade-offs they are often called to make between maximizing time and retaining capacity to fulfill their goals. It also helps to ensure that their care is aligned with their values. A deeper understanding of for whom this construct is important, what types of legacy goals people hold, and how those goals impact treatment choices is necessary to provide patient-centered whole-person care to people facing serious illness.

FUNDING

This research was funded by an NCI Diversity Supplement to the CAFÉ study, a clinic-based intervention to address financial hardship for people with cancer (CAFÉ) R01CA237322-01 Henrikson/Banegas.

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Key Messages:**What is already known on this topic**

Considering one's legacy can help people living with serious illness adapt to facing their mortality and to clarify their values and goals.

What this study adds

This study describes the types of legacy goals that impact different types of treatment choices and health behaviors.

How this study might affect research, practice or policy

Understanding the legacy goals of individuals diagnosed with serious illness can influence care planning discussions to better provide holistic person-centered care.

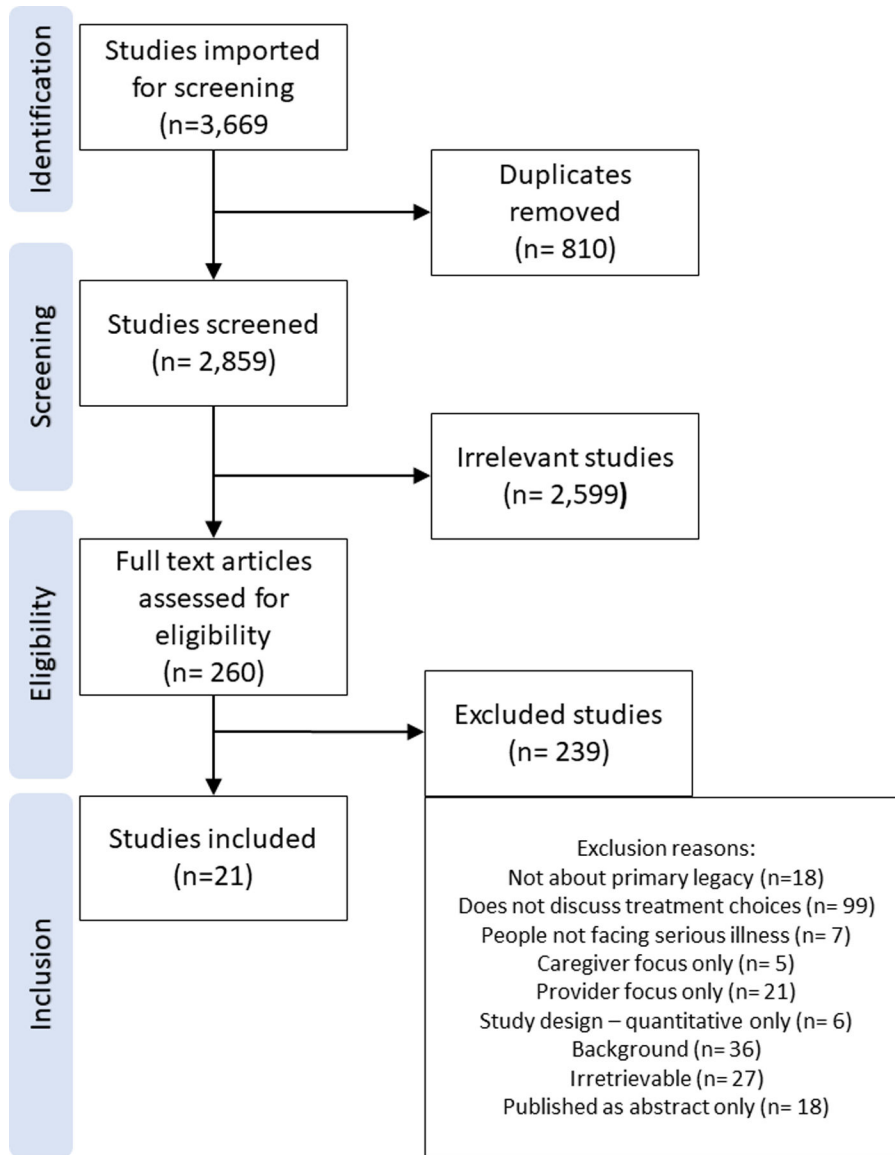


Figure 1.
PRISMA flow diagram

Primary Legacy Components

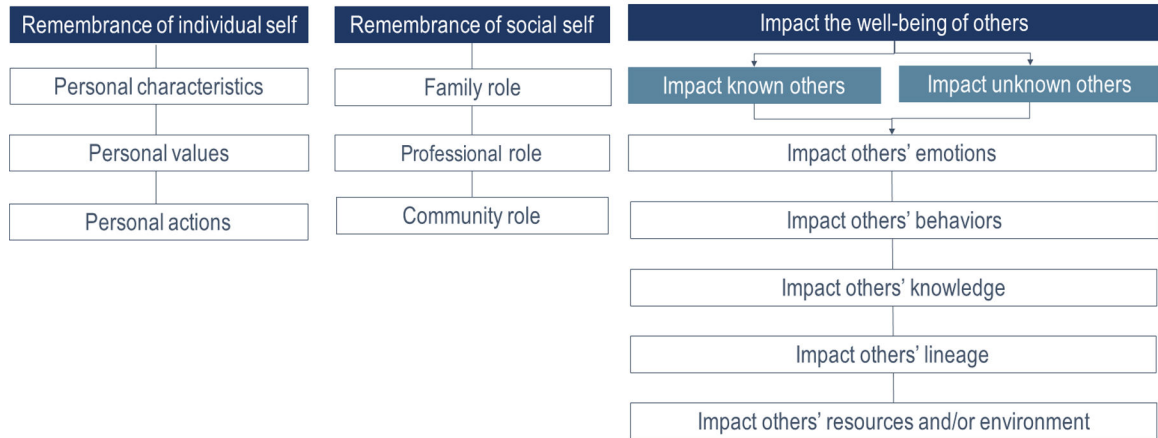


Figure 2.
Legacy goals

Table 1.

Inclusion/Exclusion Criteria

	Include	Exclude
Population	People with or facing serious illness, such as people with known family history of disease or people who have experienced a health scare, with priority focus on historically underserved/ vulnerable populations.	Clinicians, care team members Caregivers only (studies that include both patient and caregiver perspectives were included)
Concept/ Study focus	Articles that discuss, directly or indirectly how people want to be remembered after death (primary legacy) Articles that discuss how people consider legacy when making treatment choices	Articles discussing legacy of another person after their death (secondary or tertiary legacy). Articles focusing on legacy as a component of bereavement
Study designs	Empiric studies, conceptual scholarship, opinion pieces. Priority focus on studies with relevant qualitative component.	None. Lower priority focus on intervention effectiveness and feasibility studies
Literature sources	Priority sources include peer reviewed books, journal articles. Legacy-specific grey literature – reports, white papers, etc.	
Timing of search	1990-present	
Language	English	

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Table 2:

Charting Elements

Charting elements	Associated questions
Publication details	
Author	
Years of data collection	
Year of publication	
Country of origin	
Publication type	
Whether publication is open access	
Study characteristics	
Funder	
Research question	
Discipline	
Aims/purpose	
Methodological design	
Study population and demographics	
Disease state	
Disease progression	
Sample size and response rate	
Recruitment approach	
Study context	e.g., oncology, hospice
Methods	e.g., interview, focus group, intervention
Intervention type (if applicable)	
Perspective	From what perspective is research presented? E.g., Patient voices directly or commentary from author?
Findings	
Definition of legacy	What terms and key words to authors use to define legacy?
Legacy concepts/constructs	What concepts and/or constructs are included?
Theoretical frameworks	What theoretical/epistemological frameworks inform this study?
Care context	What care context does the study examine?
Treatment choices	How is legacy considered in treatment decision-making?
Material and social artifacts	What items, values or types of artifacts do people leave behind for the purposes of legacy?
Social milieu	What aspects of a person’s social milieu are discussed?
Practical steps in creating legacy	How is legacy discussed in terms of people’s labor?
Legacy tension	What types of tension regarding legacy are discussed?
How death relates to legacy	Was type and manner of death discussed as impacting or contributing to legacy?
Social personhood	How is social personhood discussed in the context of legacy? E.g., how do people think about continuing as a social presence in people’s lives after they die?
Author conclusions	What recommendations are made by the author?
Study limitations / applicability	What are the limitations in study design, population, or approach that limit interpretation applicability for the scoping review?

Table 3:

Evidence Map

Study characteristic	Number of studies	Citations
Study design		
Qualitative interview	19	(11, 20, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64, 65, 66, 67, 68, 69)
Commentary	1	(70)
Case report	1	(71)
Country		
USA	15	(11, 20, 54, 55, 56, 57, 60, 61, 64, 65, 67, 68, 69, 70, 71)
Singapore	2	(58, 63)
Canada	1	(62)
UK-Scotland	1	(53)
UK-England	1	(66)
Israel	1	(59)
Data collection		
Cross sectional	15	(11, 53, 55, 56, 57, 58, 59, 60, 61, 63, 64, 66, 67, 68, 69)
Longitudinal	4	(20, 54, 62, 65)
NA	2	(70, 71)
Nested in intervention study	5	(58, 63, 64, 65, 68)
Included caregivers	6	(53, 58, 59, 63, 67, 69)
Theoretical approach		
NR	10	(53, 55, 58, 60, 64, 65, 66, 67, 68, 69)
Phenomenology	6	(20, 54, 59, 61, 62, 63)
Grounded theory	2	(55, 56)
Narrative theory	1	(57)
NA	2	(70, 71)
Primary condition / illness reported		
Cancer	8	(20, 55, 60, 62, 66, 68, 70, 71)
Cancer / healthy	2	(11, 56)
Multiple chronic or advanced health conditions	7	(58, 61, 63, 64, 65, 67, 69)
Infertility	2	(54, 57)
Family history of serious illness	1	(53)
Not reported	1	(59)

Table 4:

Legacy concepts and definitions

Legacy Concept	Definition
Legacy	The memory of one’s self, one’s social role, and one’s impact on others.
Secondary Legacy	How someone is remembered by others known to them.
Tertiary Legacy	How someone is remembered by the public
Primary Legacy	A person’s consideration how people wish to be remembered and/or impact others before their own death.
Legacy goals	Desired outcomes of one’s primary legacy. People often take action to achieve legacy goals that impact how they are remembered and what they are able to leave behind.
Legacy creation	The process people undertake to meet their legacy goals or create legacy artifacts.
Legacy artifact	The result of legacy creation; an artifact may be tangible, such as an autobiography, legal will, or genetic data, or intangible such as one’s oral history, stories, examples, or imparted values.
Legacy impact	The desired effect of one’s legacy creation and legacy products

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Table 5.

Legacy Goal Exemplar Text

Remembrance of one’s self: I want to be remembered as/for....		
Personal characteristics:	“The only thing I think I am leaving behind is I would like to have people, now this is going to sound conceited, but think that I was a pretty nice person and an interesting person. And perhaps a person who they might see as a role model.”(11)	“The thing that’s always been in my head ‘I don’t want to die bald!’ I don’t want that to be the image for my kids. I don’t want that lasting image for my husband of me being bald and then dead. And that’s massively important.”(66)
Personal values and beliefs	“I’d never thought about legacy until I got cancer. I’d have to say cancer had the biggest role. I’m dyin’ and I want to leave something behind for my kids. I want to leave them honesty, trust in themselves and I’m always telling them to never say you can’t do somethin’ because you can.”(55)	“The legacy I’d like to leave behind is that I know that I cared for people, that I treated people well and that I respected people. I think if there’s any legacy I leave behind that’s the thing I would like people to remember about me.”(56)
Personal actions	“Will he remember that I played baseball with him or that I was lying in bed? So even when I don’t feel like it and even when I’m too tired I’ll play baseball with him cause that’s what he’ll remember ... I’m just worried I’m going to be this blank in my son’s life...I don’t want him at 20 to say, “Oh, yeah. My mom died when I was 4. I don’t remember her.’ And I’ll just be unimportant. And that may happen and I’ll be dead so it won’t affect me but it’s not what I want for him. Not at all.”(62)	“One of the things that parents can do for their children is teach them, by example, how to handle the inevitable illnesses and infirmities of aging. ... For if everything proceeds in the proper order and we all have our wits about us, parents teach their children how to die.”(70)
Remembrance of one’s social role		
Family role	“Yes, also my daughter had the baby six months old... so she wants me to stay until he is old enough to remember me...Yes, well that’s very important.” As the grandfather and patriarch of this proud, immigrant, Japanese family, this participant wanted to continue the legacy that his father and grandfather gave to him because “Family is the most important thing!(61)	Anthony wanted his dying experience to be different than his living experience...He wanted to make his sister proud of him and leave this world with dignity and on good terms with his family... “I screwed up so many years and the one thing that bothers me the most through all those years is that I knew it had a terrible affect on my sister.”(61)
Professional role	Death has made me quite conscious of the passing of time and the responsibility to see that whatever time I have left is well spent. I have a strong sense of stewardship and connectedness to those coming behind me. I developed a yearning to teach. In teaching I hope to leave a legacy of the technical knowledge I’ve accumulated.(11)	“What keeps me sane is that I have a couple of projects that if I publish will make a real contribution. If things don’t work out and I die I think I can have those published by the time I die.”(20)
Community role	“Yes, I wish to die a peaceful death. Yes, I wish for a painless death, but more important, I wish this country to continue being associated with Judaism... I wish my grandchildren to be raised as Jews, and if the fact that I will have a painless death contradicts with the more important goal of maintaining the Jewish tradition, I am willing to give that up... It is not like I am trying to present myself as a martyr, it is an Issue of priorities.”(59)	“She’s known for quite a lot of dishes...The entire family loves to eat popiah [savory spring roll]. When she cooks it, we ask everyone to come home to have it. It’s not the usual Hakka version, it’s the Hokkien version [Chinese dialect groups]. It’s really tasty. She’d always complain that it’s a lot of work, and that she’s not going to cook it the next time, but she still does it.”(63)
Impact the well-being of others		
Others’ emotions	Gregg was very close with his daughter and understood the pain and suffering that she experienced during his long illness and imminent death. He wanted to stay alive longer so that she could better prepare herself for her life after his death. “My daughter said Dad, try to not count the minutes. You have to try and be hard. She told me you know, since I’ve been this sick my family suffered so much. Especially my daughter.”(61)	“I don’t want to die in this room. I think my daughter [who lives] here is too emotional.” Patients considered the impact of the location of their death on the loved ones who were providing care.(67)
Others’ behaviors	Cancer screening and healthy lifestyles were positive behaviors they hoped to instill within their children in order to stop the negative legacy of cancer or other inheritable illnesses...” My kids are worried. My daughter has done a mammogram and she is planning on a colonoscopy. My middle son is seriously thinking that he needs to be checked. It worries all my kids and it worries me.”(56)	“They will have enough money to go through college the right way -- reading books and partying and generally enjoying life. This will show my kids that I was a fairly thoughtful father who cared for them. I am sure that they know that already and it makes me feel good.”(20)
Others’ values and knowledge	“The door is basically closed scientifically but I asked the doctor if there will be any benefit from anything that they’ve done to me to other people to help them and she said, “Definitely.” So that makes me feel good.(62)	The wish to leave a legacy took several different forms among participants. For [some], there was a keen appreciation that their medical treatment

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		experiences provide a valuable learning opportunity for health care trainees.(69)
Others' lineage	"You know, I'm still healing from the mastectomy, but it was this wait for the phone call, did my egg survive that was more emotional because it was... it felt like everything of our future was resting on that. Like if those eggs didn't survive then we had no hope at a family later."(57)	"I think with the amount of illnesses that are in our family. I want my grandchildren to have a better life than our parents, whether it is materialistically or even health wise" [Proband].(53)
Others' resources and/or environment	"Every one of them needs to work. Now, if the younger generation does not have jobs, cannot. Need to pay for the house, need to pay for the children, right? And you are lying there doing nothing every day, need to go is more scary. Never mind, I have thought this through, need to go, then have to go, to Heaven is ok. When you are old, there is nothing much, don't burden the younger generation."(58)	"It means a lot to me to have my kids ... say, 'he stuck with the cancer thing and he stuck with the hospital folks and did all the things that they asked him to do because he wanted to make things better for those that follow.' That's the legacy I want to leave." [60 y/o man](69)

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Table 6.

Legacy Goals and Treatment Choices

	Treatment Choices				Health Choices	
	Make choices about curative treatment	Make choices about fertility preservation/family building	Lower side effect or symptom burden	Make choices about end-of-life care	Modify health behaviors	Participate in health research
Remembrance of one's self						
Personal characteristics	X		X	X	X	X
Personal values	X	X	X	X	X	X
Personal actions/stories	X		X	X		X
Remembrance of one's social role						
Family role	X	X	X	X	X	X
Community/cultural role	X			X	X	
Professional role	X		X	X		
Impact others' well-being						
Impact others' emotions	X		X	X	X	
Impact others' behaviors	X			X		X
Impact others' knowledge	X	X		X	X	X
Impact others' resources/environment	X			X	X	X
Impact others' lineage		X				X

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