

Embracing the Choices of Now: Wisdom from those at End-of-Life

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Abstract

Background: There is little research focused on the elderly, despite this being the fastest-growing age group. The last phase of life brings with it unique wisdom and life advice that can be used to guide all people in their journeys. Illness or coming to an older age can begin a journey of growth and acceptance. The purpose of this study was to provide scholarship detailing advice and learnings of those in this unique and final life stage.

Methods: Nine participants were interviewed, and transcripts were analyzed in a phenomenological manner.

Results: Participants discussed topics of pain, family, and marital success. The importance of choice in the lives we live, as well as marriage as hard work, were some main trends that presented.

Conclusions: Family was the most important part of these lives; however, with or without family, one also benefits from a sense of accomplishment and pride in themselves.

Trial registration: N/A

Introduction

There is little research focused on the elderly, despite this being the fastest-growing age group (US Census Bureau, 2021). Despite some discussion on issues surrounding end-of-life, the mind of an individual who has begun the journey of processing the experiences of their life (Erikson, 1950) – what they think, feel, and say – is still unreported through literature, specifically due to the vulnerability of individuals at end-of-life. The last stage of life brings with it unique wisdom and life advice, a phenomenon that can be attested to by anyone who has been with someone who knows they are going to die. Dying is believed to “evoke a greater awareness about larger life perspectives” (Bellizzi, 2004, as cited in Montross-Thomas et al., 2018). Those who are nearer the end of their lives often attain joy and fulfillment from being able to share their stories and advice to the world (Stahnke, 2020). According to Erik Erikson, generativity – passing on pieces of oneself to a younger generation – is a necessary step to achieving a feeling of integrity at end-of-life (1950).

Literature

Further review of literature uncovers a lack of scholarship in which the purpose is to encapsulate advice and life experience from end-of-life individuals. To find relevant scholarship, this author searched through all time for literature including words “end of life” and “wisdom” or “advice” using APA PsycInfo and Academic Search Premier. Only three articles with similar constructs were found.

In one study looking at what “wisdom” meant to hospice patients, the purpose was to see how the patients’ understanding of the meaning of “wisdom” had changed after being at end-of-life (Montross-Thomas, 2018). It was found within this study that those on hospice care had shifted their overall

perspective on life; they were able to accept where they were and grow in the process. Perhaps hospice or terminal illness specifically – having the knowledge and timeframe of death – encourages growth and acceptance of one's stage in life. Another study looked at the experiences and patterns had by hospice volunteers. Themes which emerged included acceptance of dying and the value of "just being there" for patients (Foster, 2002). This study, however, did not look at what the patients' experiences of their positions were. Another study looked at the relationship between wisdom and subjective well-being at end of life (Ardelt & Edwards, 2016). The more wisdom throughout life, the less impact circumstances, including illness, have on somebody. Thus, wisdom becomes more important in adversity. The degree to which one has well-being at end of life is dependent on the growth that has happened through one's life, or acquiring of wisdom, demonstrating the importance of understanding what advice, philosophy, and regrets one may have, instilling wisdom in others – or patterns that emerge across participants – for younger generations to learn, grow, and eventually have well-being at the end of their lives.

A qualitative study explored fifteen terminally ill hospital patients' thoughts about wisdom (Wright et al., 2018). The results indicated that wisdom was perceived by the participants to be connected to a sense of humility. In addition, as one faces end-of-life, it provides an opportunity for growth in the areas of appreciating life and wanting to share lived experiences with others. One study on end-of-life used family photo albums as a tool for reflection (Testoni et al., 2020). This study's theme was linked to fundamental values and the dimensions of dignity. The highest dignity dimension was the continuity of self, which influenced all other values (Testoni et al., 2020). More studies need to be conducted to specifically offer younger populations the specific wisdom of those who have lived a full life.

Purpose

The purpose of this study was to provide scholarship detailing advice and learnings of those in this unique and final life stage. To do this, this study was offered to those who were either 80 or older or had a terminal illness. At the writing of this study, the first participant had already died. The words and experiences of those who are in this once-in-a-life period of contemplation and crystallized knowledge will receive in their lives are invaluable and believed to be able to guide others in decision-making and values, amongst other things.

Gathering narratives of these individuals helps others gather insight on how to live a life of fulfillment. These lived experiences provide insight on how to have a life worth living for individuals who have experienced Erikson's (1950) stage of generativity and arrived at the final stage of Integrity versus Despair. The purpose of this study is to allow continuous growth at the end of life while benefiting others.

Methods

Given that small sample sizes lead to a more relational and thus more in-depth collection of information (Crouch & McKenzie, 2006), participants were purposively recruited through flyers electronically distributed to hospice agencies in Salt Lake City, Utah and Colorado Springs, Colorado as well as by snowball sampling. Masters-level graduate students were also informed of the study, and one participant

was found by referral. Once contact was made with the head researcher, an in-person or phone interview was scheduled with the first author, a licensed clinical social worker with background in end-of-life care. All interviews were audio-recorded, two transcribed with Descript software and seven transcribed by hand, and all re-checked by the head researcher. All participants received a demographic questionnaire, a consent form, and the same set of questions. Some earlier participants filled out the Satisfaction with Life Scale (SWLS), though it was later determined not necessary to the current study. For those participants who were also currently married for 20 or more years, a set of questions regarding marriage was also asked.

Design

As phenomenological research aims to do, this study looks at experiences of end-of-life to understand a lesser-known phenomenon (Padgett, 2017). The experience of dying is only known by those currently experiencing it, and once they are gone, those experiences are usually gone with them. This project aimed to shed light and understanding on this unique experience as well as important life advice and lessons learned. The final psychosocial stage (Erikson, 1950) as well as the last life transition (Levinson, 1986) take place around age 65. Erikson's psychosocial stages were theorized in the 1950s when the human life span was significantly shorter; between 1960 and 2015, US life spans increased ten years from an average of 69.7 years to 79.4 years (Medina et al., 2020). Due to this increase in the average life span, this study will look at individuals who have lived past the average life span of 80 years old, or those who have a terminal illness and have the understanding that they are in their last life stage, beginning to contemplate and assess their lives as a whole.

Sample

Subjects were vulnerable due to their age and/or terminal condition. Subjects were recruited through hospice organizations and snowball sampling – the study was advertised via flyers and word of mouth and was completely voluntary. Subjects or patient care workers contacted the researcher to participate. Nine participants were attained. In conducting interviews, the licensed therapist was gentle, careful, and allowed the participant to tell their own story, including what they felt was relevant and irrelevant. As has been indicated in literature, just listening can evoke more talking for participants and is an effective therapeutic tool (Foster, 2002; Stahnke & Cooley, 2022).

Recruitment and Data Collection

The sample was collected from hospice organizations, long-term care programs, and word of mouth in communities of Southern Colorado, Utah, and South Florida. Initially, nine hospice organizations were contacted: only one participated, providing one participant. Subjects were then interviewed and surveyed with open-ended questions. Risks for participants were not anticipated. Though there were no obvious physical risks involved, possible psychological distress could not be predicted. Questions regarding regrets and life choices may have been upsetting to participants. While each participant was given full details as to the study, if anyone became upset during the interview or survey, the researcher planned to

let them know that the interview could be stopped immediately. If a participant chose not to stop but had become upset, she/he would be given a list of counseling referrals; however, nobody did become upset during interviews. Confidentiality was kept by the interviewer. Only first names, contact information, and demographic information were collected.

Measures

A five-question Satisfaction with Life Scale was administered to further understand and validate the interview data. This scale was only given to the first two participants and was deemed unnecessary to the study and future interviews. Further, in order to understand learned experiences that pertain to relationships, for those individuals who are currently in a 20+ year marriage, another set of questions pertaining to this status will be included.

Interview Questions. Interview questions that were used assessed the proudest and most regretful moments of the participants' lives, and advice that these individuals would desire to pass on to those who are younger (Appendix). There were a further seven questions asked of those who had been married for substantial periods of time without divorce; six of the nine participants had been married 25 or more years to their current or deceased partner. These participants were asked further questions regarding marriage success, partnership, and marriage experiences.

Data Analysis

After data collection, codes were used to store data anonymously. There were no foreseeable risks to confidentiality. Additional to the five-question Satisfaction with Life Scale, interview questions are below (Appendix). The categories founded are in Figure 1. Utilizing interpretative phenomenological analysis (IPA), we focused on the meaning that participants make out of their lives (Smith et al., 2013). The authors examined the transcribed interviews, seeking themes, concepts, and patterns across and within interviews. Specifically, to conduct the analysis, the following IPA strategies were employed: line-by-line analysis of the understandings of each participant; identification of emergent patterns in single cases and across cases; interpretation of what it might have meant for participants to have these experiences; and reflection of the researcher's perceptions, conceptions, and processes (Smith et al., 2013). Major themes were in at least half of the interviews.

Results

Demographics

Firstly, the only participant who spoke specifically about death was the one who was younger, on hospice care, and knew he was dying to cancer. Participants did not discuss dying directly, a trend that is relevant in this culture even in dying individuals (Foster, 2002). While there was a lack of diversity in ethnicity and sexuality, as all participants were heterosexual and non-Hispanic, other demographic characteristics varied more so. While 33% ($n=3$) were Catholic, there were also spiritual, Jewish, and Mormon ($n=1$)

participants. Across educational attainment, three had high school diplomas, three bachelor's degrees, and three graduate degrees. Further, careers were varied including trucking, business, teaching, nursing, engineering, auditing, and a governmental postal worker. Participants were from around the United States. Overall, this provides for an array of knowledge and experience across the sample.

Further, one third of the sample were male; one participant was Black while one was Native American. Given that men and Blacks have a lower life expectancy than women and Whites, these were ideal rates of each demographic group. Further, Native Americans are a lesser-populated group in the United States, adding to the diversity of the total group of participants (CDC, 2017). While two participants had terminal illnesses and medically assumed shorter life spans, the remainder for over the age of 80. There was a wide range of years married, which further provided six interviews regarding marriage longevity.

Themes

Themes of suffering, values, and passion, to include a focus on family as the central value, were founded in narrative analysis.

Suffering. Words to include “pain,” “disability,” “loss,” and “illness” were used to describe the pain in the lives of these participants. Eight of the nine participants, for 18 total times, brought up suffering in ways such as neglect, pain, disability, addiction, and loss.

“I got electrocuted by...main transformer...finger off my left hand, piece of the left hand and took use of both thumbs.” (1)

“I started acquiring back problems from about the age of 19.” (2)

“I actually turned alcoholic...stopped being an alcoholic, but don't deserve an award for that or anything.” (4)

“I lost three sisters three years ago...I lost three in 30 days.” (9)

Values. All participants spoke about values they held in order to live a good life. Beliefs and convictions specifically came up ten times in nine interviews. Taking care of one's family – commitment – came up as a central value in five interviews. Part of this means that one be selfless, committed, loyal, and honest (2; 3; 6; 7; 8). Two participants who had been married the longest (63+ years) noted that spouses should be partners and best friends – equal in every way (2; 3). Further, seven of the nine participants spoke of a faith, spirituality, or belief system that kept them strong: “God gave me the freedom to say, ‘yes’ or ‘no’” (4). Participants spoke about how so much of life is a choice. We get to choose to hold the values within our marriage that will keep it together, we choose to go for what we want, and we even have a choice in the “inability to see faults that could be a problem in [spouses]” and to “focus on much better times” (2).

Family. This theme presented with topics such as children, spouses, marriage, love, heartbreak, and family. Family was revealed to be the most important part of all participants' lives. Even for individuals

who were without children and/or spouses, family and others who fill surrogate roles for children were a significant part of the interviews. Regrets also surrounded a lack of time with family and an over-focus on work:

“I have a daughter in law who I dearly love...I call her my daughter, I speak to her almost every day, and I wish she was my daughter.” (3)

“My kids...I am so proud of them, let me tell you something...” (9)

“Our family – everyone has achieved a graduate degree.” (2)

“The most important thing I suppose...just my family.” (5)

“The one I’m with now...saw her grandkids grow up...I adored the grandkids.” (1)

One participant talked about the importance of positivity and her distress regarding the different values and unkindness in the world: “I don’t think some people should ever get married, because they make life miserable for themselves and others” (3). This participant further discussed her most important things as a good education, finding love, and having children. Another identified that “seeing children grow up” as the best part of his life (1).

Passion. When discussing what they were most proud of, all participants brought up their careers, things they had completed, or the wish to change the fact that they did not go after what they wanted as their one regret:

“Should’ve been a beautician....I should’ve focused on something that I wanted to do in my lifetime.” (8)

“I’m most thankful that I had the opportunity to go to college and get my degree, to be a part of the teaching profession.” (7)

“Being a Navy Seal.” (1)

Another participant describes that if she could change something, she would “have gotten [her] education and waited on [her] marriage. (9) The order of the important things in life was described as important by more than one participant: “First of all, getting a good education. Secondly, finding love with someone. Thirdly, raising children and being satisfied about it” while” (3).

Marriage Longevity

Six participants had been married for a long period of 25+ years and thus were asked some questions regarding their marriage and marriage in general. Two themes emerged from these questions: 1. Parents were married, and 2. Commitment/hard work. Not much was spoken about how parents’ relationships affected these participants, but of the eight people who informed the researcher about their parents, six of

the eight responded that they were married. Further, the other theme presented was that marriage requires commitment and hard work:

“There are going to be times you are not even going to want to talk to your companion – you cook the food, and you walk. That is just how things are.” (4)

A divorced participant spoke about marriage in terms of honoring the vows that each person takes. Loyalty was important and had ended some marriages:

You make the commitment. You think about the things you do. That’s the way I felt. I broke up with the first one. I made a commitment and I stuck to it. I mean I might not have liked it but I was committed... couples were switching with each other...that was the kind of thing that was going on in my group. If I was attracted to a man, I would ignore it because it goes away, that’s something that goes away. But he didn’t. (8)

Discussion

Despite all participants in this study expressing suffering within their lives, including the loss of children and spouses, physical pain and dismemberment, and illness, they saw their lives as successful and fulfilled. Suffering was introduced as a reality rather than something to be avoided. One study in older adult women who had not had children found that life satisfaction is less so associated with specific factors in life and more so in one’s embracing of whatever life brings (Stahnke et al., 2020).

Another theme demonstrated in the present interviews was life values such as spirituality – the only theme that presented in a similar study (Montross-Thomas et al., 2018). As the article details, after one comes onto hospice care, “one’s perspective shifts” (p. 1764). Perhaps illness or coming to an older age, the premise of this study, specifically begins a journey of growth, learning, and acceptance. Lessons learned are things that can be passed to those younger to live by such experiences and difficulties, as this study supports. Specifically, even more so than spirituality, family came up as the most important part of the lives of participants. However, with or without family, one also benefits from a sense of accomplishment and pride in themselves. Faith, purpose, and family allow individuals to reflect on a life well-lived, despite the presence of immense suffering in many lives.

Erikson would describe this psychosocial stage of development as ego integrity vs. despair. Ego integrity is “the acceptance of one’s one and only life as something that had to be” (1950), and later as “a sense of coherence and wholeness” (1982). In essence, if one processes their life and fulfills this stage, a sense of leaving a positive impact on society, no matter how great or small it may be, presents.

Participants with children and those lacking children all spoke about younger individuals who were surrogate children to them. Though the focus of interviews was not children, these younger people were important to the lives of participants. Interviews led to the conclusion that children become less of your identity, as can be in earlier psychosocial stages, and more of your story in the final stages of life.

Practice Implications

Aging is a lesser-studied life phase despite the important offerings of these individuals and experiences for others and for the world. At this stage, individuals go through a unique processing of their lives and are able to offer their knowledge to others, as is the purpose of this study. Practice with elders may focus on further vetting different standardized techniques for those who are not able to feel dignified at this stage. Methods such as narrative or dignity therapies (Stahnke & Cooley, 2022), largely supported by the telling and rewriting of one's story for one's own benefit, can encourage these individuals to better accept and embrace the lives they have lived rather than the lives they have not. The fulfillment of participants in the present study demonstrates the potential for others to feel this same sense of integrity in the last stages of life (Erikson, 1950).

Research Implications

Scholarship regarding the working with of individuals at end of life will both allow for academia and the larger world to learn from these individuals while they are better supported at a stage of life when there are less supports in general. A scale could be created to measure the sense of fulfillment at end of life - the main goal in these older individuals. Research can support the effectiveness of narrative therapies and dignity therapies that have demonstrated importance in this process (Martinez et al., 2017; Testoni et al., 2019). Further research can enhance the flexible support needed by these individuals, to better address their unique psychosocial challenges. Regret, strife, and personal issues still exist and verified methods of responding to the patients and these issues are necessary to a peaceful end of life experience.

Limitations

While this study assumes that being over the age of 80, if not sick, would encourage these assessments, this is a limitation as it may not be true of everyone in the same way. The nine individuals in this study expressed the having lived a full life of integrity – reflective of Erikson's final stage – but there are certainly individuals who are not as fulfilled in the lives that they have lived; this study does not encapsulate these experiences.

Conclusion

Despite suffering that was discussed across interviews, the focus was on family and finding passion in one's work. Faith was also present as a buffer against life's more difficult times while family and having a passion or purpose in life is expressed more so as what life is about. As Freud stated, "love and work are the cornerstones of our humanness." Findings support the need for individuals at end of life to be supported through standardized therapies, vetted through research studies, and the telling of one's story in this last life stage.

Declarations

Ethics approval, Consent to participate: All participants have written and verbal informed consent and the study has been approved by Newman University IRB. No other approvals were needed as no agencies were involved. No experimental measures were performed.

Consent for Publication. Not applicable.

Availability of data and material. The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

Conflicts of interest/Competing interests. No conflicts of interests exist.

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Authors' contributions. BS wrote most of the manuscript and conducted most interviews. RD conducted one interview and edited and added to the draft of manuscript. Both performed analysis.

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All methods were carried out in accordance with relevant guidelines and regulations.

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Table

Table 1. *Demographics of participants*

Category	N	%	Mean	Range
Age			83	76-91
76-80	4	44		
81-85	2	22		
86-90	2	22		
91+	1	11		
Gender				
Male	3	33		
Female	6	67		
Race/Ethnicity				
Black	1	11		
Native American	1	11		
White	7	78		
Years Married				
<20	3	33		
21-30	2	22		
31-40	1	11		
40+	3	66		
Born				
South	2	22		
Northeast	5	56		
West	2	22		
Education				
HS	3	33		
Bachelor's	3	33		
Graduate	3	33		
Religion				
Catholic	3	33		
Jewish	2	22		

Spiritual	3	33
Mormon	1	11

Note. All participants were non-Hispanic and heterosexual.

Figures

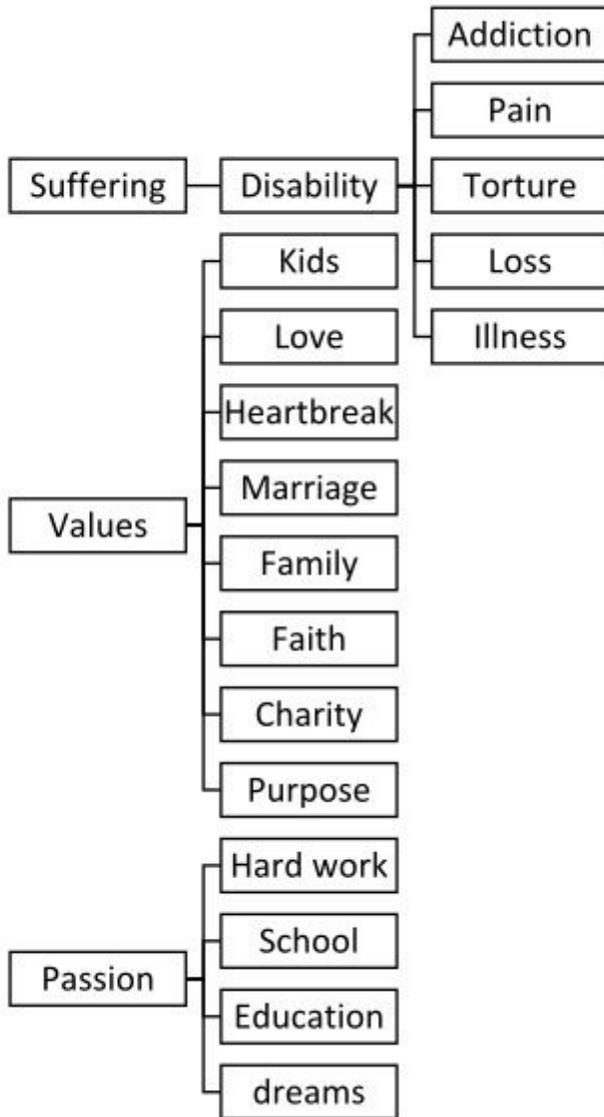


Figure 1

Pattern seen across interviews

Supplementary Files

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