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A consensual qualitative research analysis of the experience of inmate hospice caregivers: Posttraumatic growth while incarcerated

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ABSTRACT
A growing number of correctional facilities train inmates to provide end-of-life care for dying inmates. This study explores the phenomenological perspective of inmate-caregivers participating in an inmate-facilitated hospice program (IFHP) with regard to meaning and purpose in life, attitudes on death and dying, and perceived personal impact of participation. Twenty-two inmate-caregivers were interviewed at a maximum-security state correctional facility in the United States. The interviews were transcribed verbatim and analyzed using the Consensual Qualitative Research Methodology. Results suggest that participating in an IFHP may facilitate personal growth and transformation that mirrors the tenets of posttraumatic growth.

“There are two sides to survival: there is survival from death and survival for life.” (Barnett, 2009, p. 74)

Historically, inmates have been marginalized from adequate healthcare, particularly at end of life (Nelson, 2012). The population of inmates age 65 and older has grown 94 times faster than all other incarcerated populations between 2007 and 2010 (Cloyes & Rosenkrantz, 2014). Accordingly, prison-based palliative care programs are one of the nine most salient issues for the incarcerated requiring immediate attention from both the scientific and political communities (Williams, Stern, Mellow, Safer, & Greifinger, 2012). In response, some innovative correctional facilities use inmate-facilitated palliative, hospice, and/or end-of-life care programs (IFHPs) to train healthy inmates to provide end-of-life care for fellow dying inmates. Although these programs have generated public interest, including documentaries and news coverage, research or clinical endeavors have been slow to materialize. Current literature focuses on motivations of inmate-caregivers (Cloyes & Rosenkrantz, 2014), grief experiences of inmate-caregivers (Supiano, Cloyes, & Berry, 2014), and the need for hospice care in correctional settings (Stone, Papadopoulos, & Kelly, 2012; Williams et al., 2012). There is limited understanding regarding the impact of IFHPs on inmate-caregivers’ potential for growth or rehabilitation.

Posttraumatic growth (PTG)
A growing body of research suggests that traumatic and/or stressful life situations may be catalysts for positive growth (Joseph, Murphy, & Regel, 2012). “The term posttraumatic growth refers to positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (Tedeschi & Calhoun, 2004, p. 1). This concept has been noted across numerous populations, including survivors of sexual trauma (Vloet et al., 2014), war (Lee, Luxton, Reger, & Gahm 2010), illness (Adams, 2015), emergency-response workers (Ogińska-Bulik & Kobylarczyk, 2015), and offenders (Mapham & Hefferon, 2012). Additional literature suggests that incarceration (Vanhooren, Leijssen, & DeZutter, 2015) and confronting mortality (Hoelterhoff & Chung, 2013) can be traumatic events. Furthermore, research on family caregivers of individuals with cancer were noted to experience PTG as a result of their loved-ones’ diagnosis (Moore et al., 2011).

PTG is not the absence of trauma or negative psychological symptoms, but an ongoing process that may occur simultaneously with negative effects from difficult life experiences (Tedeschi, Calhoun, & Cann, 2007). An individual experiencing PTG does not return to their prior functional baseline; instead, there is a positive change from baseline (Tedeschi & Calhoun, 2004). In addition
to challenging personal beliefs about the world, Park (2004) argued that difficult life events can also impact one’s meaning in life. So not only may stressful life events prompt an individual to rethink their assumptive world but also how they think about themselves and their place in said world. Similarly, meaning-making profiles were found to be consonant with offender populations relative to non-offender populations (Vanhooren, Leijssen, & Dezutter, 2016). This suggests that inmates have the same capacity for personal meaning when compared to individuals in free society.

According to Tedeschi and Calhoun (1996) there are three broad tenets of PTG: (a) transformation in personal views of the self, (b) adjustment in the experience of relationships, and (c) change in personal life philosophy or beliefs about life. Often, specific changes within these tenets relate to the type of life event (Tedeschi & Calhoun, 2004) and/or environment where the individual spends the aftermath of the event (Tedeschi et al., 2007). This aspect of PTG is particularly relevant to inmates providing care for fellow dying inmates, because of their exposure to both death and the correctional environment.

**A positive approach to incarceration**

PTG is well noted throughout the literature; however, the potential for positive growth due to the experience of caring for the dying while incarcerated has not been explored. There is a movement within the field of criminology to adopt a positive perspective when it comes to the incarcerated (Fortune, Ward, & Willis, 2012; Maruna, 2001). Historically, the focus of the correctional system has been keeping criminals separate from society to punish and maintain public safety with only a marginal focus on rehabilitation (Campbell & Schoenfeld, 2013). Without effective and innovative programs, it is improbable for inmates to re-integrate into society and desist from criminal behavior. With the current pathology-based approach, many characteristics of inmates which may help facilitate change are not encouraged, resulting in missed opportunities to positively impact inmates (Ward & Brown, 2004). Access to programs that facilitate growth and aim to create fully functioning individuals capable of thriving, both within the walls of prison and on the outside, should be a priority.

**Purpose of study**

The substantial body of research on PTG, as well as growing research on IFHPs, suggests that the incarcerated, like other diverse populations, may benefit from difficult experiences in ways similar to the general population. Caring for the dying could be an avenue for personal growth or positive change. The aims of this study are to explore the phenomenological perspective of inmates participating in an IFHP with regard to meaning and purpose in life, attitudes on death and dying, and the perceived personal impact of participation.

**Methods**

**Participants**

**Inmate-caregivers**

Inmates were recruited from a maximum-security state correctional facility in the Northeastern United States, which we will refer to as Briarcliff Correctional Facility (fictitious name). Twenty-two inmates who were end-of-life caregivers in the IFHP at the time of interview participated. All were male and over the age of 18. Because of the sensitive nature of this population, extraneous demographic data were not collected.

**IFHP program/facility**

The Center for Hospice and Palliative Care (Cheektowaga, NY) has successfully facilitated an IFHP within the medical unit of Briarcliff Correctional Facility since 2004. Inmate-caregivers are screened and interviewed prior to acceptance into the program. Then the inmates are trained in hospice care, philosophy and techniques, including practical care assistance, existential/spiritual issues, companionship, and supportive presence by certified clinicians from the Center for Hospice and Palliative Care.

**Researchers**

As part of the Consensual Qualitative Research (CQR) process biases and expectations were discussed throughout analysis and reported here. The first author, who conducted six out of 22 interviews, is a 29-year-old, female, European-American researcher with a master’s degree in mental health counseling; experience working within the hospice setting, experience conducting CQR, and some experience interviewing inmates. The second author, who conducted five out of 22 interviews, is a 35-year-old, female, Asian-Canadian researcher with a PhD in biochemistry, experience working within the hospice setting, and experience conducting CQR. The third author, who conducted six out of 22 interviews, is a 23-year-old, male, European-American with a master’s degree in nutrition science, experience working within the hospice setting, and experience conducting CQR. The fourth author, who conducted five out of 22 interviews, is a 32-year-old, female, European-American researcher with a master’s degree in education and rehabilitation counseling, experience working within a hospice setting.
and experience conducting CQR. In addition, it is the views of these authors that hospice and palliative care should be accessible for all people, even marginalized people such as inmates. The authors also believe that all humans possess the capacity for change as well as the potential to do both good and evil.

Auditors
Auditors were used to review each stage of analysis and provide feedback based on their expertise. The fifth author is a 36-year-old, female, European-American with a PhD in personality psychology and expertise in qualitative research. The sixth author is a 54-year-old, male, European-Canadian with an M.D. in internal medicine and PhD in neurobiology with expertise in hospice and palliative medicine.

Interview procedure
In-person interviews were conducted within the Briarcliff facility over the span of 2 days in the autumn of 2014. Inmate-caregivers were informed that the decision to participate or not had no impact on their legal status or current participation in the IFHP. Written consent was obtained, then inmate-caregivers were interviewed and recorded one-on-one by researchers in a private, closed room. All audio recorded materials were secured by the researchers and destroyed upon transcription. Participants were asked 11 semi-structured questions, with follow-up questions as necessary (Figure 1). Interviews lasted approximately 25–50 min, with an average transcribed length of eight pages. Data presented here are a sub-set of a larger scale analysis.

Data analysis

Consensual Qualitative Research. Data analysis procedures followed CQR guidelines as described in Hill (2012). CQR is a data-driven qualitative methodology using a team consensus approach and including a systematic evaluation of thematic representativeness across multiple cases. The overall process of CQR is characterized by four steps: (a) conducting interviews, (b) evaluating transcripts for emergent domains, (c) converting raw data into core ideas, and (d) cross-analysis or calculating representativeness of domains and categories across all cases (Hill, 2012). The authors followed CQR guidelines for larger data sets and calculated frequency accordingly. A general label was given when 21 or 22 cases were represented, typical label with more than half of all cases or for this data set 12–20 cases, variant label equals more than 3 but less than half or 4–11 cases, and a rare label represents two to three cases.

The Consensus Approach. In accordance with CQR, at each stage the data were reviewed from multiple perspectives, including the individual level through independent review by each core team member, the group level from reaching consensus by the core team as a whole, as well as independent review by two external auditors. Each core team member must approve every aspect of analysis prior to moving forward as part of the consensus process.

Stability. Stability was established through partial coding of 17 out of the 22 transcripts and then reviewing again once the latter transcripts were added. The additional transcripts did not create any considerable changes in themes.

1. Tell me about the Hospice program.
2. What made you interested in joining the Hospice Program?
3. What does it mean to you to be a part of the Hospice Program?
4. With your experience as a hospice-caregiver, would you consider seeking a similar position after release or as a health care worker?
5. What gives your life meaning and/or purpose?
6. What are your thoughts and feelings about death and dying? Have they changed since you started the Hospice Program?
7. What has it been like for you to care for people who are dying?
8. How do you find the strength to keep going after someone you have been taking care of dies?
9. What is one thing that you wish you could tell others and/or want others to know about your experience as a Hospice caregiver?
10. How do you think caring for someone who is dying has shaped who you are today?

Figure 1. Interview questions.
Project approval

This project was approved by the State University of New York at Buffalo Social and Behavioral Sciences Institutional Review Board, the Briarcliff Correctional Facility, and the relevant State Department of Corrections. In addition, a Certificate of Confidentiality was secured from the National Institutes of Health.

Results and discussion

Confronting death and dying (D)

Analysis of the data revealed five overarching domains: Confronting Death and Dying, Personal Growth and Transformation, Program Description, Connecting with Others, and Motivation. The first two domains will be the focus of this manuscript, with discussion of many of the corresponding categories and sub-categories. The subsequent domains will be explored in a separate manuscript. Confronting Death and Dying (D) was conceptually defined as any discussion or insight into death or dying based on inmate-caregivers’ experiences. Five categories were derived from this domain; each with multiple subcategories (Figure 2).

Attitudes, thoughts, and feelings about death/dying (D1.0)

In general all participants shared their personal attitudes, thoughts, and feelings about death and/or dying (D1.0). Within this category it was typical that the participants reported a change in attitude/perception about death (D1.1) due to program participation. One inmate-caregiver reflected, “When you are dealing with death I feel that you have to look at it in a sense of it is going to happen to me. It is going to happen to people I love. I never looked at it like that before.” Another participant shared a similar sentiment, “And you know you go through life sometime and you be selfish about a lot of things but like death is like the great equalizer, it puts everything in a perspective.” It was also typical for the interviewees to express the belief that death is a natural and/or universal part of life (D1.2). Many cited that death, within the context of hospice and/or dying from a terminal illness, is something that is a part of life and that death will happen to everyone. “[Death is] something that’s gonna affect every one of us. Whether we’re prepared for it or not. Whether we’re black, white, young, old, male, female, doesn’t make a difference, it’s gonna affect every one of us.” Typically inmate-caregivers discussed the importance that no one should die alone (D1.3). Many of the participants shared how isolating death can be, especially within the walls of a correctional facility where dying inmates have limited access to family or loved ones for both security and relational reasons. One inmate-caregiver stated, “Overall, I think it’s a beautiful program for people here as well as the patients [dying inmates] ‘cause I don’t think nobody wants to die alone.” Interviewees stated with variant representativeness that death and inmate end-of-life conditions are serious (D1.4). Some inmate-caregivers talked about their experience of seeing death and dying in such a unique setting showed how serious death is and how many inmates die in the correctional facility without many things that could improve the inmate’s quality of death or life. In addition the sub-categories death is a transition (D1.5) and death is okay (D1.6) both resulted in variant

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**Figure 2.** Categories and subcategories with representativeness for confronting death and dying domain (D).
representativeness. One inmate-caregiver shared his realization about death, ‘After the training I realized that it is all right to die. I just started being comfortable with them and letting the patient know that it [death] is going to happen and not fight it. Just remember when you ready to go it is okay, I am here and I go through it with you. It is all right to die.’

Impact of caregiving for the dying (D2.0)
In general, all participants shared what it was like to be an inmate-caregiver, as well as the personal impact felt as a result. Inmate-caregivers typically stated that caring for the dying can be difficult (D2.1) including such experiences as it can be hurtful, painful, overwhelming, challenging, and can bring about feelings of sadness, grief, helplessness, and isolation. One inmate-caregiver shared, ‘When he passed, you know it hurt. I am still hurting just talking about it. I really was like close to him.’ Another expressed, ‘You get to know them and then they pass away. It hurts but it is a hurt that you don’t want to give away.’ Even though this theme focused on negative aspects of caregiving, inmate-caregivers also discussed how caring for the dying made them appreciate and value life more (D2.2). ‘They [the dying inmates] make us respect life. When you see a person take their last breath this is like, man, this is like the realest thing ever.’ Another inmate-caregiver said: ‘It made me look at life in a different way, a very different way. I don’t take life for granted.’ The balance that inmate-caregivers described, of both positive and negative aspects of caring for the dying, is congruent with current literature on PTG with non-incarcerated populations (Ogińska-Bulik & Kobyłarczyk, 2015).

Other themes that emerged from the Impact of Caregiving for the Dying category were (a) it increased knowledge and education about the dying process (D2.3), as well as (b) gave me meaning and/or purpose (D2.4). Many reported feeling a sense of purpose and meaning in spite of negative aspects of caring for the dying. One inmate-caregiver cited, It has been painful. It is crazy. It’s been beautiful. It has been meaningful. It is a lot of things.” Similarly, inmate-caregivers shared that they will use knowledge gained about death and the dying process to prepare for future personal loss (D2.5). Several inmates discussed that whether incarcerated or not, dealing with loss, and aging of family and loved-ones will definitely occur but that they now have more skills to handle difficult life experiences. “It will help me deal with the passing of my elders a little better ‘cause I’ll have a little bit more knowledge about the whole thing than I would if I didn’t participate in the program.” Caring for the dying also awakened a desire for change, a desire to lead a better life and/or made me a better person (D2.6), it shaped me (D2.7), and aided in appreciation/refocusing on important relationship (D2.8). Changes in how one views one’s self along with refocusing/increasing appreciation of important relationships are both core tenets of PTG (Joseph et al., 2012). Inmate-caregivers exhibited these signs of PTG which suggests that caring for the dying may be a catalyst for positive change.

Coping with death and the dying process (D3.0)
All participants discussed how they endured working with the dying on a continued basis. The difficulties of caring for the dying is well documented with nonincarcerated populations: home/familial caregivers (Ratkowski, Washington, Craig, & Albright, 2014), hospice volunteers (Brown, 2011), clinical caregivers (Melvin, 2012), along with some research with incarcerated populations (Supiano et al., 2014). Caring for the dying, although extremely meaningful, may lead to such pathological states as caregiver burnout (Kaličińska, Chylińska, & Wilczek-Rózyczka, 2012) or vicarious and secondary trauma (Tatano Beck, 2011). Inmate-caregivers are already at increased risk for burnout or vicarious trauma due to the isolating nature of the correctional environment, as well as the lack of access to support systems (e.g., family and loved-ones; Hochstetler, DeLisi, & Pratt, 2010). In addition, research suggests that inmates are more likely to have maladaptive coping skills or lack of adaptive coping mechanisms (Levenson, 2014). Personal coping skills are essential to any healthcare worker but especially to inmate-caregivers who have additional limitations to functioning and coping skill sets. Coping was a very salient issue for inmates in the current study, and all participants shared how they coped with the loss and stress of caring for the dying within a correctional setting.

Typically, belief in a higher power and/or an afterlife (D3.1) was cited as the primary mechanism used by inmate-caregivers to cope with confronting death and loss of the dying inmate. One inmate-caregiver stated, “I look to my higher power, and I ask Him to continue to give me the strength to continue to stay on the right path and not fall short.” Some inmate-caregivers focused on a higher power for strength while coping, whereas others saw the opportunity to care for their peers as a calling from their higher power. “You realize that it is a calling. It is something that God has bestowed upon you to do…you have to continue to do the work.” The ability to find meaning and/or purpose in a higher power during a difficult life situation is often a positive coping mechanism (Grossoehme et al.,
According to Choi, Tirrito, and Mills (2008), familial caregivers of elderly people with chronic illness and/or disabilities who used religious coping reported lower depression and caregiver stress, allowing religious copers to care for loved-ones at home longer. Although the current study methodology did not allow for baseline of spiritual functioning and religious coping is not the same exact construct as spiritual growth, belief in a higher power and/or an afterlife (D3.1) was a prevalent finding. The conclusions that can be drawn from the finding are limited but suggest that spirituality and religion play a role in how this group of inmate-caregivers copes with caring for the dying.

Memorializing and/or remembering the deceased (D3.2) was also used by inmate-caregivers to cope; this theme showed variant representativeness. One inmate-caregiver shared, “I know they wouldn’t want me to be down on my luck because before they passed away they said, listen, life don’t stop. As long as you can still breathe and as long as you can still help someone you keep doing what you got to do.”

Others reflected on how remembering the deceased gave them strength to connect with other dying inmates and not give up. Another coping mechanism was the use of team support (D3.3) such as connecting with other caregivers during team meetings, attending monthly support group meetings, and talking with mental health staff. Although many inmate-caregivers did not see each other in general population or outside of meetings, they attributed their continued success as hospice caregivers to knowing they were connected to others sharing similar experiences. One inmate-caregiver reflected, “I talk to my peers and I get it off my chest and they [other hospice aides] listen. They just let me get it off and then they fill me up with encouragement.” Psychosocial support is essential to any caregiving relationship. A recent study on volunteer caregivers for people with AIDS found that lack of social support was a predictor of caregiver burnout (Akintola, Hlengwa, & Dageid, 2013).

Another coping mechanism reported with variant representativeness was connecting with the self (D3.4) through journaling, self-reflection, and taking time for rest; this was also reported to be helpful in dealing with continued confrontation with death and dying. Inmate-caregivers also attributed realistic expectations and knowledge about death/the dying process (D3.5) as a variant coping mechanism. It was the increased understanding of death/the dying process that allowed the interviewee to see changes occur in the dying inmate, which helped the inmate-caregiver not be surprised or caught off-guard when death occurred.

I am not going to go in here with a distorted reality, like this person was going to miraculously survive. I got to keep myself under control enough to understand that this person is going to die. I can’t have the type of attitude that is pessimistic because he is going to die. I got to be optimistic for this person but at the same time not giving him a fake reality.

Finally, it was a sense of responsibility and/or duty (D3.6) to the dying inmate that the interviewees cited as another coping mechanism. Many of the inmate-caregivers looked at their position as an essential duty and one that did not afford the luxury of giving up.

You continue on because like I said, I can’t just quit. That’s not the only patient. There are a lot of patients and there’s gonna be many more to come. So if everybody was to fall apart when their patient dies, then it would have no palliative care, you would have no hospice.

Many of the interviewees believed that no one should die alone, and if they were to quit the program they feared that would result in the inmates dying alone. This sentiment propelled many of the caregivers to keep caring for the dying inmates as well as cope with the hardship of caring for the dying: “It is not about you. It is about the patient. Just because this patient has passed away, of course, we wish that he didn’t die, however, there is another patient who is waiting in the wings that you have to care for.”

The final two sub-categories for Coping with Death and the Dying Process involve caregivers making sense of death. Inmate-caregivers attributed realistic expectations and knowledge about death/the dying process (D3.5) as variant coping mechanisms. It was increased understanding of death/the dying process that allowed interviewees to feel prepared when the inmate died.

I am not going to go in here with a distorted reality, like this person was going to miraculously survive. My whole thing is all right, I got to keep myself under control enough to understand that this person is going to die. I can’t have the type of attitude that is pessimistic because he is going to die. I got to be optimistic for this person but at the same time not giving him a fake reality.

Others discussed the difficult balance between making the dying inmate feel safe and connected while maintaining boundaries. Finally, a sense of responsibility and/or duty (D3.6) was cited as another coping mechanism. Many inmate-caregivers looked at their position as an essential duty.

You continue on because like I said, I can’t just quit. That’s not the only patient. There are a lot of patients and there’s gonna be many more to come. So if everybody was to fall apart when their patient dies,
then you would have no palliative care, you would have no hospice.

Many interviewees believed that no one should die alone (D1.3), which propelled caregivers to keep caring for dying inmates and cope with the hardship of caring for the dying: “It is not about you. It is about the patient. Just because this patient has passed away, of course, we wish that he didn’t die; however, there is another patient who is waiting in the wings that you have to care for.”

This idea of coping through a sense of duty or responsibility is echoed in previous research. Supiano et al. (2014) found that a sense of duty and focusing on future dying inmates who need care helped some inmate caregivers manage their grief experience as hospice caregivers. Coping with the personal realization of death, the difficulties associated with caring for the dying and the loss of the person being cared for are core aspects of the inmate-caregiver experience. It is important to address these needs for inmates who care for the dying. At Briarcliff, inmate-caregivers are monitored by mental health professionals and receive ongoing support. Moving forward, additional research should be conducted with regard to inmate-caregivers’ mental health and well-being.

**Preparedness for one’s own death (D5.0)**

This category was discussed typically and focused on personal mortality. Typically the participants reported an increased awareness of personal mortality (D5.1). One inmate caregiver reflected that caring for the dying, “gives me a certain consciousness of my mortality. When you see what can happen it changes how you live your life and how you do your thing, how you do the things in your life.” Another typical concern is that inmate-caregivers did not want to die alone/would want others to care for them (D5.2). Many of the inmate-caregivers, as they became more aware of their personal mortality, pictured themselves in the same position as the dying-inmate. One interviewee reflected, “I don’t ever want to be in that position [dying in a correctional facility] but if I had to be I would be glad that somebody was sitting there with me like I was sitting there with him.” Coming to terms with personal mortality is no easy feat and can be a powerful and complex existential realization. In spite of the negative aspects of coming to grips with personal mortality, including fear, anxiety, hopelessness, and loss of meaning in life, research suggests positive growth can occur as well (Wong & Tomer, 2011). Many inmate-caregivers viewed this new perspective on life and death as a positive experience in spite of intense or mixed feelings about mortality and loss; some even saw the experience as a catalyst for personal change. Horne (2009) referred to this experience as the *vitality of death*, a term first coined by Koestenbaum (1971); this concept explains change that can result once personal mortality is brought to the surface of consciousness and can no longer be ignored. “Vitality in the sense that the acceptance of our mortality may enable us to approach limits and vicissitudes in life with great resourcefulness and clarity-lies in the ability to hold the tension in the uncertain certainty: we know that we shall die but know not when” (Horne, 2009, p. 61).

**Personal growth and transformation (T)**

Twenty-one of 22 participants discussed topics within the domain of Personal Growth and Transformation (Figure 3). This domain emerged consensually as any change and/or desire to change beliefs, worldview, character, behavior, and/or thinking due to hospice program participation. Multidimensional changes reported

<table>
<thead>
<tr>
<th>Category/Subcategory</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1.0 The Program Changed/Shaped Me</td>
<td>Typical</td>
</tr>
<tr>
<td>T2.0 Transformation in Thoughts/Attitudes</td>
<td>Typical</td>
</tr>
<tr>
<td>T2.1 Changed my perspective/opened up my mind</td>
<td>Variant</td>
</tr>
<tr>
<td>T2.2 Increased knowledge/ education</td>
<td>Variant</td>
</tr>
<tr>
<td>T2.3 Less judgmental/more tolerant</td>
<td>Variant</td>
</tr>
<tr>
<td>T3.0 Transformation in Feelings/Emotions</td>
<td>Typical</td>
</tr>
<tr>
<td>T3.1 Increased compassion/empathy/patience</td>
<td>Typical</td>
</tr>
<tr>
<td>T3.2 Increased/allowed self to be vulnerable</td>
<td>Variant</td>
</tr>
<tr>
<td>T3.3 Less bitter/angry/resentful</td>
<td>Variant</td>
</tr>
<tr>
<td>T4.0- Transformation in Character</td>
<td>General</td>
</tr>
<tr>
<td>T4.1 Appreciate life more</td>
<td>Typical</td>
</tr>
<tr>
<td>T4.2 Became more selfless</td>
<td>Typical</td>
</tr>
<tr>
<td>T4.3 Became a better person/man</td>
<td>Variant</td>
</tr>
<tr>
<td>T4.4 Provides sense of worth</td>
<td>Variant</td>
</tr>
<tr>
<td>T4.5 Self-revelation/awakened a part of me</td>
<td>Variant</td>
</tr>
<tr>
<td>T4.6 Made me someone I never thought I could be</td>
<td>Variant</td>
</tr>
<tr>
<td>T5.0 How the Hospice Program Promotes Growth/Change</td>
<td>Typical</td>
</tr>
<tr>
<td>T5.1 Growth from helping the dying</td>
<td>Typical</td>
</tr>
<tr>
<td>T5.2 Program offered opportunity for change</td>
<td>Variant</td>
</tr>
<tr>
<td>T5.3 Growth from developing relationships</td>
<td>Variant</td>
</tr>
</tbody>
</table>

**Figure 3.** Categories and subcategories with representativeness for personal growth and transformation domain (T).
ranged from changes in thoughts/attitudes, to feelings/emotions, as well as more global changes in character. Participants also discussed self-realizations related to personal growth, including changes in perception of self. More than half explicitly stated that the program changed or shaped them (T1.0). “It [the hospice program] is something that changed my life and changed my perspective of, everybody says 360, I say 180. It changed my whole viewpoint of life and living around.” Another remarked, “It [caring for the dying] shapes you into a person that you never thought you could be. A person you actually like.” According to Joseph et al. (2012), changes in how a person views themself have been linked with PTG. Although the exact manifestation may vary, some examples include, “a greater sense of personal resiliency, wisdom and strength, perhaps coupled with a greater acceptance of their vulnerabilities and limitations” (Joseph et al., 2012, p. 19).

Transformation in thoughts and/or attitudes (T2.0)
Inmate-caregivers typically discussed the impact that caring for the dying had on personal thoughts, attitudes, and/or perspectives. With a variant representativeness, participants noted a positive change in perspective, as well as an opening up of their mind (T2.1). One participant reflected, “You go through life sometime and you be selfish about a lot of things but like death is like the great equalizer, it puts everything in a perspective.” In addition, inmate-caregivers stated that it increased knowledge and education (T2.2). One participant shared that he had worked in a hospital setting before but never directly caring for the dying; it was joining the hospice program that increased his knowledge and understanding.

When I started the hospice program, the death part wasn’t really shocking to me because in [date omitted] I worked as [healthcare-related job]. So I seen the same stuff but I didn’t know as much as I know about it now. I’m much more informed and much more prepared now that I’m actually participating in helping these people with their transition.

Finally, inmate-caregivers attributed program participation to personal changes making them less judgmental and/or more tolerant of others (T2.3). One inmate-caregiver shared that a family member had been raped, and the rage he felt about that situation, but how one of his first hospice assignments also had a record for rape. Over time the inmate-caregiver learned to look beyond what the inmate may have done.

You know, the humanity of him being with [a degenerative disease], the humanity of him not being able to brush his own teeth or comb his own hair, it like takes that defense down. I don’t look at him like, “ahhhhh!!” I look at him like, “you need help.”

The response of participants suggests that caring for the dying may in fact help shape thoughts and perspectives. This transformation should be viewed as a rehabilitative bonus to the programmatic solution of meeting inmates’ needs for care at end-of-life. Additional research should explore the impact on inmate-caregiver attitudes and perspectives resulting from caring for the dying.

Transformation in feelings and emotions (T3.0)
It was typical for inmate-caregivers to report a positive transition in feelings and/or emotions as a result of participation in the hospice program. Interviewees typically discussed an increase in compassion, empathy, and patience (T3.1).

Caring for someone and for me this hospice program has opened up a part of me that I never thought was there, a thing called compassion and empathy. I used to be so angry, you know, and now the only thing I am angry at is that why did I wait so long to learn about this other part of me that wants to help people?

Inmate-caregivers also described a metamorphosis with regard to increased allowance of being or showing vulnerability (T3.2). This finding is particularly unique within correctional settings because research on male inmates suggests that incarceration increases hegemonic masculinity, such as showing dominance and beliefs that males should be socially superior (Ricciardelli, Maier, & Hannah-Moffat, 2015). Inmate-caregivers in the current study, however, discussed an increased ability to be vulnerable and also shared that being vulnerable or open to others was a change they noted in other life situations, not just while caring for the dying. Participants often described this transformation through metaphors such as breaking through or chipping away hardness, letting down shields, taking off armor, etc.

When you work in hospice with the patients, you let everything out. You take off that extra coat, your armor. They show you pictures of how they used to be and you seeing what he is going through. You know how hard it is for him. You have to help him go to the bathroom, hold him up. How could you keep that shield up around him?

Participants also reported a reduction in feelings of bitterness, anger, rage, and resentment (T3.3). Not only did they report allowing themselves to be more open and exposed to others but also felt less volatile emotions.

I used to be easily irritated. My mind used to go from 0 to 1000 if you ticked me off. A lot of bitterness and I felt
that I had to keep this air of hostility projected from me to keep people away from me because that is my safety zone. But since now if somebody ticks me off I got people I go talk to about it. And I am good now. I have this peace on the inside.

Learning empathy as a new skill or way of being is an example of how inmate-caregivers changed, as well as an example of positive growth from difficult life situations. There is support that adversity is linked with increased capacity for empathy, which is a precursor to active compassion as well as an essential aspect of prosocial behavior (Lim & Desteno, 2016). Inmate-caregivers who reported increased capacity for empathy and compassion may have the potential to function in a more prosocial and adaptive manner. In addition, according to Bock and Hosser (2014), cognitive aspects of empathy predicted recidivism in a longitudinal study of both violent and nonviolent youth offenders. Cognitive aspects of empathy include “a cognitive process that enables a person to understand or identify another person’s psychological perspective” (Bock & Hosser, 2014, p.102). In short, youth offenders who scored low on empathy, or on the ability to relationally connect with another’s experience, were more likely to end up back in the correctional system. In a meta-analytic review of inmates/offenders and empathy, an inverse relationship was noted between empathy and recidivism; most participants reported a conversion of both violent and nonviolent youth offenders. Cognitive aspects of empathy include “a cognitive process that enables a person to understand or identify another person’s psychological perspective” (Day, Casey, & Gerace, 2010). Future studies should seek to evaluate the longitudinal effects of participating in an IFHP as well as its relationship with recidivism and dissidence.

Transformation in character (T4.0)

Although many participants reported changes in aspects of the self (e.g., thoughts, attitudes, feelings, and/or emotions), it is notable that nearly all interviewees within this domain (21 out of 22) reported a conversion in character as well. Inmate-caregivers typically shared that they appreciated life more now (T4.1). One inmate reflected,

I think we all die slowly daily. It gives you a better appreciation for what you do have in your life. Whenever your family leaves home you always tell your family that you love them. You never know what that day may bring.

Another inmate shared how caring for the dying had awoken the realization of the fragility of life.

The hospice program really made me appreciate life more on a higher scale. It made me appreciate my family and made me appreciate my wife, my kids, my mom and things like that because it just made me realize that life is so precious and it can be taken away from you at any time.

Increased appreciation for life or valuing life more has been noted as one of the core tenets of PTG. According to Vanhooren et al. (2015), released offenders reported growth with reference to increased appreciation for life, as well as valuing support from loved-ones as a result of experiences during incarceration. Typically participants reported a shift in focus from themselves to others and this transition made them feel they had become more selfless (T4.2). Many interviewees attributed being selfish to their incarceration; some also mused that had they thought of others before they might not be in their current situation. One inmate-caregiver shared, “You know what it does is like it did it really revealed the selfishness that I have within myself. It gave me an awareness of the needs of other people. It is about sacrificing. You sacrificing yourself.” Interestingly, they also reported that the whole process made them into a better person/man (T4.3). Many discussed how participating in the program helped them to redefine what it means to be a man or a good man: “Whether I disagree or agree with their lifestyle or what they have done, I care about the individual, the person. I am learning to look at them with a different set of eyes and it is making me, I am becoming a man.”

Many participants explored the common and singular view of what it means to be a man, especially in a correctional facility and how that has changed. Another said “I have learned to be a better husband. I have learned to be a better father and this has come through hospice.”

Several interviewees discussed how caring for the dying gave them a sense of worth (T4.4). This subcategory included feelings of duty, purpose, responsibility, and pride. One participant expressed,

You do wrong all your life and you kind of look at it as this worthlessness that you have. But then this kind of gives me worth. It gives me that I am worth something. Not doing bad and evil but I am worth something to somebody. That I can do good in people. I can be a blessing and not a curse in people’s lives.

In addition, inmate-caregivers noted a self-revelation or awakening within (T4.5); referring to positive aspects of themselves that they were either unaware they possessed or had never had the opportunity to demonstrate. Inmate-caregivers also reported that it made them someone they never thought they were capable of being (T4.6). “I feel like becoming part of the hospice program I was actually made to realize that I can be a caregiver. I can be a person who actually takes care of someone and understands that this person needs help.”

How the hospice program promotes growth and change (T5.0)

In addition to exploring changes in self, it was typical that interviewees discussed how participating in the hospice
program was a catalyst for said changes. Three main themes that emerged from this category were growth from helping the dying (T5.1), program offered opportunity for change (T5.2), and growth from developing relationships (T5.3). It was typical for inmate-caregivers to cite that growth occurred from helping the dying (T5.1) and this was the most prevalent theme with regards to how the program promotes growth and change.

It [caring for the dying] made me a better man. It made me look at what someone needs to go on. It made me realize that life is very short sometimes. And it made me realize that no matter what, you gotta do the right thing for someone at least once in your life.

Bearing witness to the end-of-life struggle and subsequent death of a fellow human being and fellow inmate is something that interviewees reported as significantly impactful, as well as what aided in their personal growth. Seeing a person, which for many participants, was like looking into the future, provided a jolt to their thinking, feeling, and acting in the world that helped them change on a life-altering level. “For me experiencing hospice showed me another side. There is so much you can learn from the dying. The dying teaches the living.”

Limitations and future research

This project is a starting point for the larger discussion of access to end-of-life care for the incarcerated, as well as positive or growth-oriented inmate rehabilitation. Follow-up studies should include pre–post measures or trajectories with regard to individuals participating in IFHPs. Although the current study did not collect demographic information to preserve privacy, future research should explore whether specific characteristics of inmates correlate with the likelihood to participate as a peer-caregiver, potential for growth/rehabilitation, and/or other individual factors that may contribute to the understanding of IFHPs. In addition, there needs to be exploration and standardization of IFHPs. This study also only evaluated one program and one cohort of caregivers. Follow-up studies should be multisite, use standardized measures, and be longitudinal in nature. Another limitation is that some of the themes which emerged were related to the questions asked. This may be due to the nature of semistructured interviews but more likely the correctional environment. Time was restricted and spontaneity to move from the introduced topics was limited. Another limitation of conducting research within the correctional environment is that access to the inmate-caregivers was constrained to 2 days, which did not allow for concurrent data collection and analysis that can be advantageous in qualitative research to promote theoretical sampling and exploration of emergent themes. Future research should seek to include these important aspects.

Conclusions

There appears to be potential for inmate-caregivers participating in an IFHP while incarcerated to display attributes that are characteristic of posttraumatic growth. Through confronting death and dying, finding personal meaning and opportunity, as well as building significant relationships, inmate-caregivers have the potential for positive growth and personal transformation. Based on the experiences of inmate-caregivers who participated in the current study, being involved in an IFHP can help facilitate a growth process for inmate-caregivers that includes impacting perceptions on death and dying as well as creating meaning and purpose in their lives. Since caring for the dying can be extremely difficult, it is important to train and support inmate-caregivers with regard to coping, realistic expectations about death and disease progression, and social support to reduce potential for caregiver burnout. In addition, the potential for transformation of inmate-caregivers participating in an IFHP must be taken into consideration and further explored. Inmate access to quality end-of-life care and meeting the unique needs of a growing aged population continues to be a complex issue that warrants future attention.

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