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Effect of Online Palliative Care Training on Knowledge and Self-Efficacy of Direct Care Workers

Abstract

We evaluated the effectiveness of an online training on palliative care knowledge and self-efficacy among intellectual and developmental disability (IDD) staff using a one-group pretest-posttest design. IDD staff from four non-profit residential and day services organizations in a U.S. Midwestern state participated. Among 132 staff who completed a baseline assessment, a 2-hour online training, and a posttest, 98 staff completed a 1-month follow-up survey. Palliative care knowledge was assessed before and after the training, and palliative care self-efficacy, at baseline and 1-month follow-up. We used linear regression to identify the factors that influence the effect of the training on main outcomes. Overall palliative care knowledge and self-efficacy significantly improved while higher education and longer work tenure enhanced training effectiveness.

Keywords: intellectual and developmental disabilities, direct care workers, online training, palliative care, evaluation
**Introduction**

Direct care workers (DCWs) play a critical role in the lives of people with intellectual and developmental disabilities (PWIDD) to support good health, community integration, and independence (Espinoza, 2018). **DCW is a general term referring to individuals who provide the majority of long-term care or personal assistance services for older adults or people with disabilities or chronic conditions (PHI National, 2020).** This encompasses direct support professionals (DSPs) in the intellectual and developmental disability field, as well as nursing assistants in the long-term care field. As PWIDD live into adulthood and experience chronic or life-threatening health conditions (Coppus, 2013; Lauer & McCallion, 2015; Patja et al., 2000; World Health Organization & The World Bank, 2011), direct care workers (DCWs) are increasingly needed to provide palliative care services (McCarron et al., 2010; Todd, 2005). Palliative care is a holistic model of care that focuses on the alleviation of suffering and on improving quality of life by meeting the physical, social, psychological, cultural, and spiritual needs of people with chronic and life-limiting illnesses and their families (World Health Organization, 2015). Staff in the intellectual and developmental disability (IDD) field have shown a lack of knowledge and efficacy in providing palliative care (Cartlidge & Read, 2010; Fahey-McCarthy et al., 2009; Ng & Li, 2003; Ryan et al., 2010). This incorporates issues such as communication, end-of-life (EOL) decisions, care before and after death, and cultural competency, among others.

PWIDD can have widely differing capacities for communicating - understanding and expressing themselves through language (Regnard et al., 2007). Cognitive and motor-related disabilities can make it difficult for PWIDD to communicate their care needs such as expressing discomfort or pain (Stein, 2008). Meaningful communication with PWIDD frequently depends
on the ability of caregivers to recognize and translate a language of signs and behaviors (Regnard et al., 2007). Therefore, staff assessment of PWIDD distress or pain and health status is critical (Friedman et al., 2008; Regnard et al., 2007). Patients’ difficulty in understanding their own condition is another issue (citation removed for masked review; Stein, 2008). In a study with DCWs (citation removed for masked review), participants discussed communication difficulties in situations where PWIDD were not able to understand the changes in their health and why they could not participate in certain activities as before. A survey with directors of hospice, palliative care, and IDD service providers also identified communication challenges due to IDD clients’ inability to understand their illnesses (Stein, 2008). Disclosure of life-limiting illness or death to PWIDD is also an important communication issue. Stakeholders, such as family members and IDD staff, may disagree about whether PWIDD should be told the truth (Tuffrey-Winje, 2013), as well as be emotionally overwhelmed in conveying bad news (Tuffrey-Winje, 2013). Verbal and non-verbal communication skills have been shown to be necessary to break bad news with IDD nursing staff in residential settings (Ng & Li, 2003).

According to a 2009-2010 survey with a United States (US) representative sample, approximately 26% of US adult consumers have advance directives (Rao et al., 2014). Although no data for PWIDD is available, it is assumed that PWIDD are much less likely to have advance directives (Guinn & Winston, 2018). While there is no law prohibiting PWIDD from completing advance directives (Guinn & Winston, 2018), the current law rather encourages all people including PWIDD to exercise their rights of self-determination (Patient Self Determination Act, 1990). Most PWIDD residing in long-term care facilities, nevertheless, are unable to plan EOL decisions in advance or express their wishes in an EOL situation (Lohiya et al., 2003). PWIDD without advance directives or a proxy decision maker (e.g., family members, friends) could
suffer unnecessarily with respect to medical, legal, and administrative problems (Friedman et al., 2008; Lohiya et al., 2003). It is important to communicate with, educate, and provide EOL-related information to the individuals serving as proxies (Friedman et al., 2008) and the entire care team (Lohiya et al., 2003; Sherman & Branum, 1995).

IDD staff have been shown to struggle with care provision before and after death (Botsford, 2004; Tuffrey-Wijne et al., 2007). This can include assessing and managing pain (Fahey-McCarthy et al., 2009; Friedman et al., 2008), providing proper nutrition and hydration (Fahey-McCarthy et al., 2009; Friedman et al., 2008), caring for someone who is dying (Hahn & Cadogan, 2011; Todd, 2004), and care after death (Hahn & Cadogan, 2011; Ng & Li, 2003).

Cultural competency issues also can be a challenge for IDD staff in providing palliative care for PWIDD (Fahey-McCarthy et al., 2009; Hahn & Cadogan, 2011; Ng & Li, 2003). Needs assessment and training evaluation studies have recognized the importance of developing cultural competency in a multicultural health care context (Fahey-McCarthy et al., 2009), cultural awareness about how a body is cared after death (Ng & Li, 2003), and the importance of recognizing cultural background and experiences of IDD staff and clients (Hahn & Cadogan, 2011).

Bereavement-related issues, such as perception of death, understanding grief and bereavement of PWIDD, providing supports for PWIDD and family members at the time of bereavement, and self-care strategies are serious challenges that IDD staff face (Cross et al., 2012; citation removed for masked review; Tuffrey-Wijne et al., 2017). Learning the concept of a good death was identified as an educational need in a survey with IDD staff (Ng & Li, 2003; Tuffrey-Wijne et al., 2017). Training about bereavement is warranted as well to provide supports
for PWIDD through an improvement in staff’s efficacy (Reynolds et al., 2008) and knowledge (McEvoy et al., 2012; Raab, 2014; Richards et al., 2010; Watters et al., 2012).

Due to the stress involved in working with PWIDD who have serious illness, self-care strategies are needed. Methods that foster mindfulness and self-awareness to improve well-being, have been shown to be effective with a range of health professionals (Cross et al., 2012; Raab, 2014; Richards et al., 2010).

To date, there is a limited literature on the effectiveness of palliative care training for IDD staff. Codling et al. (2014) evaluated a one-day EOL training for 43 paid caregivers in the United Kingdom (UK). The training included PWIDD’s understanding of death, EOL care, pain evaluation and monitoring, documenting PWIDD’s EOL wishes, and recent guidance on hospice care (Codling et al., 2014). Participants were asked to rate their satisfaction with the training and how it may affect their practice (Codling et al., 2014). Training effectiveness cannot be determined due to a lack of information about participant status pre-training.

Hahn and Cadogan (2011) evaluated an 8-hour palliative care train-the-trainer curriculum with 64 staff from five development centers in the US. Participants worked in the disciplines of dietary/nutrition, medicine, nursing, pastoral care, psychology, and social work. The curriculum covered a wide range of palliative care topics including care plan development, spiritual and cultural context, pain assessment and management, hospice care, EOL, and grief and bereavement. Satisfaction with the training and the effectiveness of the training was evaluated using survey questionnaires upon conclusion of the training (n=58) and at two years post training (n=25). There was a significant improvement in confidence with respect to palliative care provision and overall preparedness (Hahn & Cadogan, 2011). DCW participation in the training and evaluation, is unclear, based on the findings.
Cross et al. (2012) evaluated a 2-day EOL care training for IDD staff from UK care homes. Training for IDD staff included EOL care, communication regarding dying and death, bereavement, and self-care strategies. The training was evaluated using data from discussions and interviews with management and staff (Cross et al., 2012). Despite the overall positive response, it is unclear whether DCWs participated in the evaluation.

Another US study (Friedman et al., 2008) evaluated the effect of a training program regarding EOL care and do-not-resuscitate (DNR) protocol on a variety of clinical staff in a pediatric skilled nursing facility for individuals with severe developmental disabilities and medical problems. There was a significant increase in participant acceptance with stopping feedings for a dying patient prior to death. DNR knowledge, however, did not improve. For example, there was no significant difference in identifying DNR components pre- and post-training (Friedman et al., 2008).

A quasi-experimental design study (Reynolds et al., 2008) was conducted with 33 staff members of a community-based IDD service agency in Ireland to evaluate the impact of a training program on knowledge and confidence in supporting PWIDD at the time of bereavement. The 2-day training included key concepts of loss and bereavement, the experience of bereavement of adults with intellectual disabilities, and guidelines for supporting individuals with IDD (Reynolds et al., 2008). Each the training (n = 17) and control (n = 16) group completed questionnaires about confidence in supporting PWIDD at the time of bereavement, attitudes to and knowledge of bereavement, and perceptions of support and satisfaction at work at the beginning and 2-week post training (Reynolds et al., 2008). Confidence in supporting PWIDD at the time of bereavement was similar between the two groups before training, but the level of confidence among the training group was significantly higher than that of the control
group post training (Reynolds et al., 2008). A methodological concern with the study, however, was that the training group was composed of individuals who identified bereavement training as a need, whereas the control group was selected from those expressing an interest in the training, but not bereavement as a concern (Reynolds et al., 2008).

In another study in UK (Watters et al., 2012), a 6-hour training program about bereavement and grief in PWIDD was evaluated for its effect on support staff knowledge using a wait-list control group experimental design, with 24 support staff members randomly assigned to the experimental group and 24 assigned to the wait-list control group. The experimental group completed a questionnaire before and after training and 1-month post training. The control group completed a questionnaire at the same time, and took the training prior to the follow-up questionnaire (Watters et al., 2012). The questionnaire included 10 open-ended questions about the process of grieving in the general population, the grieving process for PWIDD, and supporting PWIDD through bereavement. Responses were scored based on a list of predetermined response categories. Scores after training were significantly higher than those before training in both groups, though it is unknown whether the increased level of knowledge was maintained after 1 month due to a lower 1-month follow-up response rate (31.3%) (Watters et al., 2012).

Prior palliative care and bereavement evaluation studies highlight the importance of training IDD staff about diverse palliative care topics and positive impacts of such training in some areas. Despite the contributions, there are several issues in existing studies that limit the validity or applicability of findings. Use of inadequate study design or methodology, such as collecting data only after the training without the pretest (Codling et al., 2014) and assigning participants in a way that could introduce selection bias (Reynolds et al., 2008), undermines the
validity of study results. Small sample sizes and low response rates across studies make it difficult to quantitatively compare the training effects on different groups or at different time points. Only half of the reviewed studies clearly involved DCWs in their training or reported DCW-specific results (Codling et al., 2014; Reynolds et al., 2008; Watters et al., 2012). In addition, except for a few studies (Friedman et al., 2008; Hahn & Cadogan, 2011), most were conducted in the UK or Ireland, in which social and health care contexts may be considerably different from those of the US.

This pilot study filled gaps in the literature and in evaluated studies by evaluating the effectiveness of an online training on palliative care knowledge and self-efficacy among IDD staff (mainly DCWs) who serve PWIDD in a US Midwestern state.

Methods

The effectiveness of an online training on palliative care knowledge and self-efficacy was evaluated using one-group pretest-posttest design. The training was developed based on the literature (Codling et al., 2014; Cross et al., 2012; Friedman et al., 2008; Hahn & Cadogan, 2011; Reynolds et al., 2008; Watters et al., 2012) and needs assessments (two citations removed for masked review). The 2-hour training included modules on the overview of palliative care, legal and ethical issues, cultural diversity and competency, communication with PWIDD, symptom management, EOL care and logistics after death, bereavement and grief of PWIDD, and staff grief and coping strategies. The audio-recorded streaming video incorporated a variety of elements, including lectures, case studies, embedded videos, review questions, and reflections.

Recruitment

Several non-profit community-based organizations serving PWIDD were contacted to recruit direct care workers who were working with the title of “direct support professional” or
those who served in a managerial or clinical position but had complete “direct support professional” training. Participants were recruited with flyers and letters that were distributed throughout the organizations and explained the study.

**Process**

Online palliative care training was delivered using an Internet-connected tablets to staff who work at four community-based service organizations in northern Illinois. Informed consent was obtained before conducting the training and associated evaluations. Before taking the training, participants answered questions about palliative care knowledge and palliative care self-efficacy as well as demographic and work-related information. Participants took a posttest about palliative care knowledge upon completing the training. One month after the training, participants were invited via email to complete an online follow-up survey that included items on palliative care self-efficacy and questions for training evaluation. They were given 1 month to complete the survey.

**Instruments**

Palliative care knowledge was objectively assessed using 30 multiple-choice or true-false questions that test participants’ understanding of the training content. It included questions on the overview of palliative care (three items), legal and ethical issues (five items), cultural diversity and competency (three items), communication with PWIDD (three items), symptom management (three items), EOL care and logistics after death (three items), bereavement and grief of PWIDD (six items), and staff grief and coping strategies (four items). Some examples are: “What is the definition of palliative care?” “Which of the following is a good communication tip when working with PWIDD?” “When a death has occurred, the must be called within 24 hours of the death.”
Due to the lack of instruments specifically assessing palliative care self-efficacy of IDD staff, the authors developed a palliative care self-efficacy instrument by selecting relevant items from the existing palliative care and EOL care literature in IDD and non-IDD fields (Adriaansen et al., 2005; Bekkema et al., 2015; Fahey-McCarthy et al., 2009; Gerhardt et al., 2009; Hahn & Cadogan, 2011; Hobday et al., 2010; Kirkendall & Waldrop, 2013; McCarron et al., 2010; McEvoy et al., 2012; Ng & Li, 2003; Nochomovitz et al., 2010; Phillips et al., 2011; Ryan et al., 2010; Ryan et al., 2011a; Ryan et al., 2011b; Stein, 2008; Todd, 2013; Tuffrey-Wijne et al., 2007; Wark et al., 2014; Wittenberg-Lyles et al., 2014) and the authors’ own needs assessment result from focus group and survey data from IDD staff (two citations removed for masked review). **Self-efficacy is defined as “people's judgments of their capabilities to organize and execute courses of action required to attain designated types of performances”** (Bandura, 1986, p. 391). Since self-efficacy is a domain-specific concept, palliative care self-efficacy refers to an individual’s belief in his or her own ability to be competent in providing palliative care (Adriaansen et al., 2005). Palliative care self-efficacy was measured with 11 items using a question “How confident are you regarding the following?” with five Likert-style responses of not at all (1), slightly (2), somewhat (3), moderately (4), and a lot (5). Summing the points (ranging 1-5) of 11 items, named “palliative care efficacy score” yielded scores ranging from 11 to 55.

**Analysis**

Sample characteristics were examined using percentages and means. Chi square tests were used to examine the differences in the frequency distribution of affirmative responses (moderately or a lot) to individual palliative care self-efficacy items between the baseline and follow-up. The association between continuous variables, such as years in the IDD field,
palliative care knowledge score, and palliative care self-efficacy score, was examined using Pearson’s correlation or Spearman’s correlation.

Differences in main outcome scores (palliative care knowledge score and palliative care self-efficacy score) by demographic or work-related characteristics were examined using an independent t-test or analysis of variance (ANOVA). When the outcome scores of two groups had unequal variances, the Welch’s t-test (Ruxton, 2006) was used instead of a Student’s t-test. A F-star test was used when the assumption of equal variance was not met. The F-star test is similar to a one-way ANOVA, but it can be used under conditions of unequal variances and unequal means across groups (Wilcox et al., 1986).

Regarding main outcomes, four hypotheses were tested: (1) palliative care knowledge improves between pretest and posttest; (2) palliative care self-efficacy improves between baseline and follow-up; (3) higher education and longer tenure in the IDD field enhance the improvement in palliative care knowledge, controlling for the condition at pretest; and (4) higher education and longer tenure in the IDD field enhance the improvement in palliative care self-efficacy, controlling for the condition at baseline.

A paired t-test was used to compare the palliative care knowledge scores before and after the training and palliative care self-efficacy scores at baseline and the 1-month follow-up. Effect sizes were examined to determine practical significance of the changes in palliative care knowledge and palliative care self-efficacy between before and after the training using Cohen’s d (Ialongo, 2016). Cohen’s d is considered small if the value is 0.20 or less, medium if the value is 0.50 or greater, large if the value is 0.80 or greater, and very large if the value is 1.30 or above (Maher et al., 2013).
Since some of main outcome scores were not normally distributed, non-parametric statistical methods (Wilcoxon rank-sum test, Kruskal-Wallis test, and Wilcoxon signed rank test) were also used to compare the results with those from respective parametric tests (independent t-test, ANOVA, and paired t-test). The literature, however, recommends parametric statistical methods such as a t-test and ANOVA over non-parametric methods when sample sizes are moderate or large (n > 30) and skewness or kurtosis is low (Rasch & Guiard, 2004).

Linear regression was used to identify the factors that may influence the effect of the training on palliative care knowledge and self-efficacy. The change in palliative care knowledge score between pretest and posttest was regressed on education level (4-year college education or not) and tenure in the field (years in the IDD field), controlling for the pretest knowledge score. The change in palliative care self-efficacy score between baseline and 1-month follow-up was regressed on education level (at least 4-year college education or not) and tenure (years in the IDD field), controlling for the baseline self-efficacy score.

The study was approved by the University Institutional Review Board and the participating organizations' review processes, and informed consent was obtained prior to participant completion of the baseline survey.

Results

Sample Characteristics

Table 1 summarizes sample characteristics at baseline and 1-month follow-up. Among 132 staff members who completed a baseline assessment, 2-hour online palliative care training, and a posttest, 74% (n = 98) participated in a 1-month follow-up survey. The majority of those who completed both baseline and follow-up assessments were female (89%) and White (58%) or African American (35%). Approximately 45% had less than an associate degree and 37% were
in rural areas. On average, participants were 39 years old (20-67) and worked for 10 years in the field (1-30). Though similar in other characteristics, participants who completed both the baseline and follow-up survey (n = 98) had a higher education level than those who completed the baseline survey only (n = 34) (p < .005, Fisher’s exact test).

Table 1 about here

**Palliative Care Knowledge**

Table 2 presents the palliative care knowledge score at pretest and posttest by demographic and work-related characteristics. The overall knowledge score significantly increased from pretest to posttest in a paired t-test (mean 24.2 to 26.5, p < .00005, n = 132). The increase was 7.7 points on a 100-point scale. The effect size of the change in palliative care knowledge score between pretest and posttest, calculated using Cohen’s d, was 0.79 (95% confidence interval 0.54-1.04), which is considered large (Maher et al., 2013). The overall knowledge score was different by gender (male > female), race (White > Black), education level (more education > less education), and location (rural > non-rural) at both pretest and posttest in a t-test, ANOVA, a F-star test. There was no difference in overall level of palliative care knowledge by job title (DCW vs. other) either at pretest or posttest in a t-test.

Table 2 about here

**Palliative Care Self-Efficacy**

Table 3 presents the distribution of individual palliative care self-efficacy items at baseline and 1-month follow-up by the frequency and percentages of affirmative responses (moderately or a lot). Since the Palliative Care Self-Efficacy scale was developed for and used in this study for the first time, there are no other studies that can be compared for the scale score.
Internal consistency tests indicated good reliability as indicated by Cronbach’s reliability coefficients (0.88 at baseline and 0.86 at follow-up) (George & Mallery, 2003).

There was a significant improvement in five individual self-efficacy items between the baseline and 1-month follow-up in chi square tests: utilizing advance directives, telling PWIDD bad news, what to do when a client dies, identifying grieving behaviors of PWIDD, and helping PWIDD recover after loss. No significant change was observed in six self-efficacy items: responding to ethical problems, communicating with people of different backgrounds, recognizing pain, non-medical pain management, caring for patients before death, and managing personal grief.

Table 3 about here

The overall self-efficacy score significantly increased from baseline to follow-up in a paired t-test (40.9 to 44.6, \( p < .00005, n = 98 \)). The increase was 8.4 points on a 100-point scale. The effect size of the change in palliative care self-efficacy score between baseline and 1-month follow-up was medium as indicated by Cohen’s d 0.56 (95% confidence interval 0.27-0.85) (Maher et al., 2013).

Independent t-tests showed a lower self-efficacy score among rural staff at baseline (38.9 vs. 42.1, \( p < .05 \)), but no difference at follow-up (43.4 vs. 45.3, \( p > .05 \)). Longer work experience (years in the field) was positively correlated with the overall self-efficacy score at follow-up (Spearman’s rho 0.24, \( p < .05 \)). There was no significant difference in self-efficacy score by other demographic or work-related characteristics either at baseline or at follow-up.

**Factors Affecting Improvement of Palliative Care Knowledge and Self-efficacy**

Regression analysis indicated a positive effect of higher education in enhancing the effect of training on palliative knowledge and a similar effect of tenure in the field on palliative care.
self-efficacy. Having a bachelor’s degree or higher education was associated with more improvement in overall palliative care knowledge (coefficient 1.33, p < .0005), controlling for the knowledge pretest score. Working longer in the field was associated with more improvement in overall palliative care self-efficacy (coefficient 0.13, p < .05), controlling for the baseline self-efficacy score.

Discussion

The results indicate the effectiveness of the online training in improving palliative care knowledge and self-efficacy of staff serving IDD clients. The different influence of demographic and work-related characteristics on the effect of the training suggests the factors to consider in the development of palliative care continuing education for DCWs who serve PWIDD.

To our knowledge, this is the first study that evaluates the effectiveness of an online training on palliative care knowledge and self-efficacy among staff serving PWIDD. Including a considerable number of DCWs in rural and suburban areas in the US in the evaluation is another strength of this study. The large and moderate effect sizes on knowledge and self-efficacy indicate the effectiveness of online format training as well as the feasibility of reaching a larger number of DCWs, particularly those in rural areas.

Although palliative care knowledge increased overall, having a bachelor’s degree or higher education was associated with more pronounced improvement in palliative care knowledge between pretest and posttest. Given this finding, training may be modified so that staff with less education can understand the training material better. This might be achieved by using easier terminology and adding more diverse case studies. Adding games and simulations in the curriculum would provide more contextual learning experiences. For example, educational games that incorporate real-life scenarios, can be integrated in the training. Such games have
been shown to help students really absorb the learning materials through experiential learning (Day-Black et al., 2015). Similarly, simulation experiences on topics such as ethical and cultural competency challenges, can be utilized. Participants can work through real-life problems and develop collaboration and communication skills in the simulation process (Boothby et al., 2019). Modules on topics needing more reinforcement also might be delivered as stand-alone trainings. Research has shown that DCWs prefer interactive continuing education delivery with more frequent, shorter sessions (Menne et al., 2007).

Participants working in rural areas demonstrated significantly lower levels of palliative care self-efficacy at baseline. The difference, however, disappeared at follow-up, indicating the effect of the training in closing the gap between rural and suburban areas in palliative care self-efficacy. The finding that the effect of training on palliative care self-efficacy is greater for staff with more work experience in the field is not surprising. Providing effective and practical strategies in training may help less experienced staff improve palliative care self-efficacy. Additionally, training may be improved by focusing on the aspects related to the self-efficacy items with no significant improvement in this evaluation.

Our results indicate a lack of improvement in self-efficacy in ethics, cultural competency in communication, pain assessment, non-medical pain management, caring for patients prior to death, and management of personal grief. The lack of improvement, however, may be due to different reasons. Self-efficacy in communicating with people of different backgrounds may have not improved significantly because a very high percentage of participants (91.8%) were already confident about it before the training. A considerable proportion of participants (69.4%-72.5%) were also confident about their ability to respond to ethical problems, recognize pain, and manage personal grief before training. The training may have not been effective enough to
significantly increase the number of participants who became confident about these areas. For example, PWIDDD may not recognize the signs of illness nor be able to communicate these issues to IDD staff (citation removed for masked review; Stein, 2008). Staff, therefore, must learn how to interpret the language that PWIDDD are using (Regnard et al., 2007). How to interpret PWIDDD’s communication styles or expressions regarding pain was not part of the training. The training on non-medical pain management and caring for patients prior to death did not significantly improve self-efficacy in these two areas. More detailed and step-by-step guidance may be added to strengthen the training in these areas.

The use of convenience sampling in a small geographic area limits generalizability of results. IDD staff’s background and working conditions may vary across different types of organizations and areas in the US. The small size of the follow-up sample prohibited examination of other factors that might affect the effectiveness of the training in regression models. We did not ask participants about their palliative care experience in the baseline survey because participants were not familiar with the term “palliative care” and educating them about the concept was part of the training. Providing the definition of the term prior to the training would have interfered with the evaluation of the training effect. Using newly created instruments is another limitation. The questions on palliative care knowledge and self-efficacy were developed specifically for this study due to a lack of appropriate instruments. Therefore, the validity of the summary measures has not been examined, and comparing our results with those from other groups is not possible. While we could examine some degree of information retention with the 1-month follow-up survey, this certainly does not indicate that the information was retained long-term. To truly assess information retention, a longer time period is needed. Lastly,
lack of comparison groups prohibited a firm conclusion since the result could not be compared with that of other groups without the training.

Future research may improve on this study by using a more rigorous study design (e.g., experimental design with a control group) with a larger and diverse sample. Identifying less effective parts of the training through item analysis of knowledge and self-efficacy items will guide us to improve the training and evaluation more specifically.
References


https://doi.org/https://doi.org/10.1111/j.1365-2648.2004.03268.x


https://doi.org/10.1097/01.NEP.0000000000000340


https://doi.org/10.1002/ddrr.1123


https://doi.org/10.1007/BF00540908


https://doi.org/10.1111/j.1741-1130.2007.00142.x


Tuffrey-Wijne, I., Hogg, J., & Curfs, L. (2007). End-of-life and palliative care for people with intellectual disabilities who have cancer or other life-limiting illness: a review of the


http://www.who.int/mediacentre/factsheets/fs402/en/


[Two references removed for masked review.]
Table 1

Sample Characteristics

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<td>10.2</td>
</tr>
<tr>
<td>Job title</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCW</td>
<td>110</td>
<td>83.3</td>
<td>80</td>
<td>81.6</td>
</tr>
<tr>
<td>Other</td>
<td>22</td>
<td>16.7</td>
<td>18</td>
<td>18.4</td>
</tr>
<tr>
<td>Years in the field</td>
<td>10.2 (mean)</td>
<td>1-32 (range)</td>
<td>10.1 (mean)</td>
<td>1-30 (range)</td>
</tr>
<tr>
<td>Location</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>47</td>
<td>35.6</td>
<td>36</td>
<td>36.7</td>
</tr>
<tr>
<td>Non-rural</td>
<td>85</td>
<td>64.3</td>
<td>62</td>
<td>63.3</td>
</tr>
</tbody>
</table>

*Note.* DCW = direct care worker.
Table 2

**Palliative Care Knowledge Score Pre and Post Training by Demographic Characteristic**

<table>
<thead>
<tr>
<th></th>
<th>Pretest</th>
<th></th>
<th>Posttest</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Mean (SD)</td>
<td>p-value</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
<td>26.3 (1.87)</td>
<td>&lt;.0005^1</td>
<td>27.6 (1.40)</td>
</tr>
<tr>
<td>Female</td>
<td>117</td>
<td>23.9 (2.96)</td>
<td></td>
<td>26.4 (2.98)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>71</td>
<td>25.3 (1.90)</td>
<td>&lt;.001^2</td>
<td>27.7 (1.78)</td>
</tr>
<tr>
<td>Black</td>
<td>51</td>
<td>22.5 (3.24)</td>
<td></td>
<td>24.9 (3.34)</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>24.7 (3.74)</td>
<td></td>
<td>26.3 (2.86)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>24</td>
<td>22.2 (2.98)</td>
<td>&lt;.00005^3</td>
<td>24.3 (3.17)</td>
</tr>
<tr>
<td>Some college</td>
<td>47</td>
<td>23.7 (2.79)</td>
<td></td>
<td>25.7 (2.64)</td>
</tr>
<tr>
<td>Associate degree</td>
<td>12</td>
<td>25.2 (2.44)</td>
<td></td>
<td>27.2 (2.24)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>37</td>
<td>25.3 (2.68)</td>
<td></td>
<td>28.0 (2.21)</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>12</td>
<td>25.8 (1.99)</td>
<td></td>
<td>28.5 (1.08)</td>
</tr>
<tr>
<td><strong>Job title</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCW</td>
<td>110</td>
<td>24.1 (2.93)</td>
<td>&gt;.05^1</td>
<td>26.3 (2.92)</td>
</tr>
<tr>
<td>Other</td>
<td>22</td>
<td>25.1 (2.86)</td>
<td></td>
<td>27.4 (2.47)</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>47</td>
<td>25.0 (2.23)</td>
<td>&lt;.01^1</td>
<td>27.2 (1.93)</td>
</tr>
<tr>
<td>Non-rural</td>
<td>85</td>
<td>23.7 (3.18)</td>
<td></td>
<td>26.1 (3.21)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>132</td>
<td>24.2 (2.94)</td>
<td></td>
<td>26.5 (2.87)</td>
</tr>
</tbody>
</table>

*Note.* SD = standard deviation. DCW = direct care worker. ^1From an independent t-test of subgroups at the time point. ^2From a F-star test of subgroups at the time point. ^3From analysis of variance of subgroups at the time point. ^4From a paired t-test of pretest and posttest scores.
### Table 3

**Affirmative Responses to Palliative Care Self-Efficacy Items Pre and Post Training**

<table>
<thead>
<tr>
<th></th>
<th>Baseline (n=98)</th>
<th></th>
<th>Follow-up (n=98)</th>
<th></th>
<th>p-value¹</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>%</td>
<td>Frequency</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Respond to ethical problems</td>
<td>71</td>
<td>72.5</td>
<td>81</td>
<td>82.7</td>
<td>&gt; .05</td>
</tr>
<tr>
<td>Utilize advance directives</td>
<td>61</td>
<td>64.2</td>
<td>77</td>
<td>78.6</td>
<td>&lt; .05</td>
</tr>
<tr>
<td>Communicate with people of different backgrounds</td>
<td>90</td>
<td>91.8</td>
<td>87</td>
<td>88.8</td>
<td>&gt; .05</td>
</tr>
<tr>
<td>Telling people with IDD bad news</td>
<td>68</td>
<td>69.4</td>
<td>83</td>
<td>84.7</td>
<td>&lt; .05</td>
</tr>
<tr>
<td>Recognizing pain</td>
<td>71</td>
<td>72.5</td>
<td>83</td>
<td>84.7</td>
<td>&gt; .05</td>
</tr>
<tr>
<td>Non-medical pain management</td>
<td>47</td>
<td>48.0</td>
<td>59</td>
<td>60.2</td>
<td>&gt; .05</td>
</tr>
<tr>
<td>Caring for patients before death</td>
<td>50</td>
<td>51.0</td>
<td>61</td>
<td>62.2</td>
<td>&gt; .05</td>
</tr>
<tr>
<td>What to do when a client dies</td>
<td>45</td>
<td>45.9</td>
<td>70</td>
<td>71.4</td>
<td>&lt; .0005</td>
</tr>
<tr>
<td>Identify grieving behaviors</td>
<td>57</td>
<td>58.2</td>
<td>79</td>
<td>80.6</td>
<td>&lt; .005</td>
</tr>
<tr>
<td>Helping people with IDD recover after loss</td>
<td>55</td>
<td>56.1</td>
<td>74</td>
<td>75.5</td>
<td>&lt; .01</td>
</tr>
<tr>
<td>Managing personal grief</td>
<td>68</td>
<td>69.4</td>
<td>79</td>
<td>80.6</td>
<td>&gt; .05</td>
</tr>
</tbody>
</table>

*Note.* IDD = intellectual and developmental disabilities; ¹From a chi square test to examine the differences in the frequency distribution of affirmative responses between the baseline and follow-up surveys.