



12-2023

Delirium Education for Family Caregivers of Patients in the Intensive Care Unit: A Pilot Study

Amanda Wheeler

Elise Bloch

Sarah Blaylock

James Root

Kateriza Ibanez

See next page for additional authors

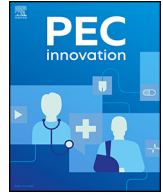
Follow this and additional works at: https://digitalcommons.sacredheart.edu/ot_fac



Part of the [Occupational Therapy Commons](#)

Authors

Amanda Wheeler, Elise Bloch, Sarah Blaylock, James Root, Kateriza Ibanez, Newman Newman, Jose Diarte, and Louis P. Voigt



Delirium education for family caregivers of patients in the intensive care unit: A pilot study

Amanda Wheeler^{a,*}, Elise Bloch^b, Sarah Blaylock^c, James Root^d, Kateriza Ibanez^a, Kristine Newman^a, Jose Diarte^a, Louis P. Voigt^e

^a Department of Neurology, Memorial Sloan Kettering Cancer Center, NY, USA

^b Occupational Therapy Department, Nova Southeastern University, Fort Lauderdale, USA

^c Occupational Therapy Department, Jacksonville University, Jacksonville, USA

^d Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, NY, USA

^e Anesthesiology & Critical Care, Memorial Sloan Kettering Cancer Center, NY, USA

ARTICLE INFO

Keywords:

Caregiver training
Caregiver delirium education
ICU delirium

ABSTRACT

Objectives: Delirium, an acute change in mental state, seen in hospitalized older adults is a growing public health concern with implications for both patients and caregivers; however, there is minimal research on educating caregivers about delirium. Utilizing family caregivers to assist with delirium management in acute care settings demonstrates improved health outcomes supporting the need for patient and family centered care. The primary aims of the study were to determine feasibility of implementing a delirium education video for caregivers of patients in an adult oncology intensive care unit and compare delirium knowledge to caregivers in a control group.

Methods: A quasi-experimental design comprised of 31 family caregivers of adult patients in an oncology intensive care unit to determine feasibility of implementing a delirium education video.

Results: The results demonstrate feasibility of implementing a caregiver education video in-person and virtually. While total delirium knowledge scores were not statistically significant, knowledge gained within the delirium presentation subgroup was significant ($p = .05$).

Conclusion: This study demonstrates feasibility of implementing a caregiver education video and findings support further research in this area.

Innovation: Collaborating with caregivers to develop virtual video education for delirium allows for a versatile approach to connect with caregivers to support their caregiving role.

1. Introduction

Over the past decade, the health care landscape has shifted placing a greater emphasis on patient and family-centered care, which recognizes the patient as well as family feedback as a marker for successful outcomes [1]. Several health care organizations have adopted a patient- and family-centered approach to care with greatest enculturation seen within pediatric health care settings [2,3]. The practice of patient- and family-centered care has key tenets including respect for the individual, open sharing of information, active participation of patients and caregivers, and collaboration with patients and caregivers in the development of systems and delivery models [4]. One setting that would benefit from family caregiver integration is the adult intensive care unit (ICU), where family caregivers serve an essential role because they often act as patient advocates and provide physical and emotional support to the patient [5,6]. The Society of Critical Care

Medicine (SCCM) supports family caregiver integration into the ICU care team; however, there continues to be a gap in caregiver integration [7].

Delirium, an acute fluctuating change in mental state [8], is a condition that is widely prevalent in hospitalized older adults, and a growing public health concern because of its negative impact on patients and their caregivers [9-11]. Delirium has a myriad of risk factors, including being above the age of 65, having a critical illness, a diagnosis of cancer, baseline cognitive impairments, and undergoing a surgical procedure, among others [12]. Delirium is an independent predictor of increased mortality, hospital length of stay, readmission, and long-term cognitive and functional impairments [13-16]. Because of the multitude of consequences from having delirium, individuals often become dependent on their family caregivers [10].

Family caregivers are often fearful of patients presenting with delirium and report a greater amount of distress compared to the patient when interviewed after having delirium [10]. Despite feelings of fear, family

* Corresponding author at: Department of Neurology, Memorial Sloan Kettering Cancer Center, NY, USA.
E-mail address: wheeler2@sacredheart.edu (A. Wheeler).

caregivers seek information from the care team to learn about delirium. While existing research is limited, integration of the family caregiver to assist with delirium prevention and management can reduce caregiver anxiety and uncertainty [17].

The family caregiver plays a key role in the care, decision making, and outcomes of hospitalized patients and may experience physical and emotional burden as a result [17-20]. Existing evidence demonstrates engagement of caregivers by the health care team increases their activation in the care of their loved one and reduces strain on the caregiver [2]. Family caregivers experience, training, and perceived satisfaction is influenced by multiple factors and should be considered when developing family caregiver resources [4]. Successful caregiver education approaches include standardization of information provided, integration of a problem-based approach, use of multimedia, and follow-up to initial education sessions [21,22].

There is minimal research on family caregiver delirium education provided within acute care with lesser information specific to the ICU [16]. In a study designed to assess the efficacy of a delirium education brochure for use in a hospital setting, the results demonstrated limited dissemination of the brochure, and family outcomes were not reported [23]. In a survey study administered to non-ICU family caregivers of patients with Alzheimer's, family caregivers were interested in learning about delirium, and their preferred modality for receipt of information was through in-person, internet-based, or print resources [24]. While there are published data on the impact of multidisciplinary efforts to reduce delirium incorporating volunteer and caregiver intervention [25-27], there is limited published data on adult ICU specific family-centered care approaches for delirium management and no studies were found specific to collaboration with caregivers to develop delirium education.

The primary aims of this pilot study were to determine the feasibility of implementation of a delirium education video for family caregivers and to compare knowledge about delirium in caregivers who received the education versus those who did not. Additional measures related to anxiety and caregiver satisfaction were also assessed; however, this publication will focus on the primary aims of the study.

2. Methods

2.1. Development of the family caregiver delirium education video

During the delirium education development phase, partnership was established with the hospital patient education committee and the Patient and Family Advisory Council for Quality (PFAQC), both considered key stakeholders and experts in development of caregiver health education content. The patient education committee, comprised of hospital staff trained in patient education and health literacy best practices as well as volunteer patients, caregivers, and health professionals, are assigned to the development of hospital patient and caregiver educational resources. The PFAQC, comprised of patients, family caregivers, and hospital administrative and medical staff, works together to ensure the patient's and family voices are heard and incorporated in hospital projects, processes, and committees.

Several steps were taken in development of the Family Caregiver Delirium Education Video including an initial informal needs assessment through one-on-one interview with a caregiver of a former hospital ICU patient who had delirium. A presentation and information gathering session to PFAQC was conducted where members provided feedback on level of interest and perceived need for education on delirium. Additionally, PFAQC provided input regarding mode of educational delivery and other suggestions. Once a video was determined as the best mode based on existing literature and feedback received from PFAQC, video development occurred in close partnership with the patient education committee. The patient education committee provided ongoing instrumental feedback throughout the video development process (e.g., health literacy guidelines, visual imaging, and cultural sensitivity).

The Family Caregiver Delirium Education Video was approximately 5-min in length with animations and a voice over recording on delirium

risk factors, signs/symptoms, and ways for family members to provide non-pharmacological interventions. The video integrated a case scenario requiring the viewer to demonstrate knowledge learned.

2.2. Study design, setting & participants

The study was a quasi-experimental design, comprised of a convenience sampling of family caregivers of patients in an adult oncology mixed medical surgical ICU. Prior to initiation of the study institutional review board approval was obtained. The family caregivers were related or unrelated to the patient and they were individuals who provide support and with whom the patient had a significant relationship; they included the patient's spouse/partner, child, parent, grandparent, sibling, or other close relative/friend. In the instance where there were several family caregivers, caregivers were presented with the information and determined themselves who would participate.

Criteria for caregiver inclusion were as follows: the family caregiver was ≥ 18 years of age, spoke fluent English, and had a minimum of a 6th grade education level. The patient of the family caregiver was ≥ 65 years of age and was a medical or surgical patient. Participants were excluded from the study if the patient had a prior stay in ICU during the current hospital admission and/or receiving comfort care only.

2.3. Procedures

Recruitment and survey administration occurred by two occupational therapists; both were not treating therapists of the patient to minimize conflict of interest. Caregivers were identified within 72 h of a patient's admission to the ICU by daily screening of the ICU census and communication with the bedside nurse to determine the primary family caregiver of the patient. Upon determining eligibility and obtaining informed consent to participate in the study, caregivers were randomized to either the control or intervention group (Fig. 1). Randomization was accomplished by utilization of Research Electronic Data Capture (REDCap) electronic data capture tools.

2.4. Intervention

In phase one of the study, participants assigned to the control group received the Caregiver Delirium Knowledge Questionnaire (CDKQ) and the Hospital Anxiety and Depression Scale - Anxiety subsection (HADS-A) immediately upon enrollment via REDCap either in-person or via email. Participants assigned to the intervention group received the CDKQ and HADS-A after viewing the delirium education video. The initial study design did not include a virtual component, but as a result of COVID-19 and restricted visitation, the study was modified to allow for virtual or in-person participation.

All participants were offered to complete the study either virtually or in-person. Intervention group participants who viewed the video in-person watched via iPad in the patient room due to visitor restriction to only being in patient room; the researcher was present in the room during viewing. The HADS-A and CDKQ were completed at the end of viewing the video on the iPad. A printed copy of the handout summarizing video content was provided to the caregiver.

Intervention group participants who completed the study virtually were provided instructions via telephone with a follow up email including the video and handout link with written instructions for completing the questionnaires. The email was sent during the call with verbal confirmation by participant it was received. Participants were given the option to view the video while remaining on the phone or view within 24 h of receiving and complete the questionnaires after viewing the video. All participants were provided with the researcher's contact information and instructed to call with any questions after viewing the video.

In phase two of the study, both the intervention and control group were given the Family Satisfaction in the Intensive Care Unit Survey-24 (FS-ICU 24) within 72 h of a patient's discharge from the ICU either in-person or via

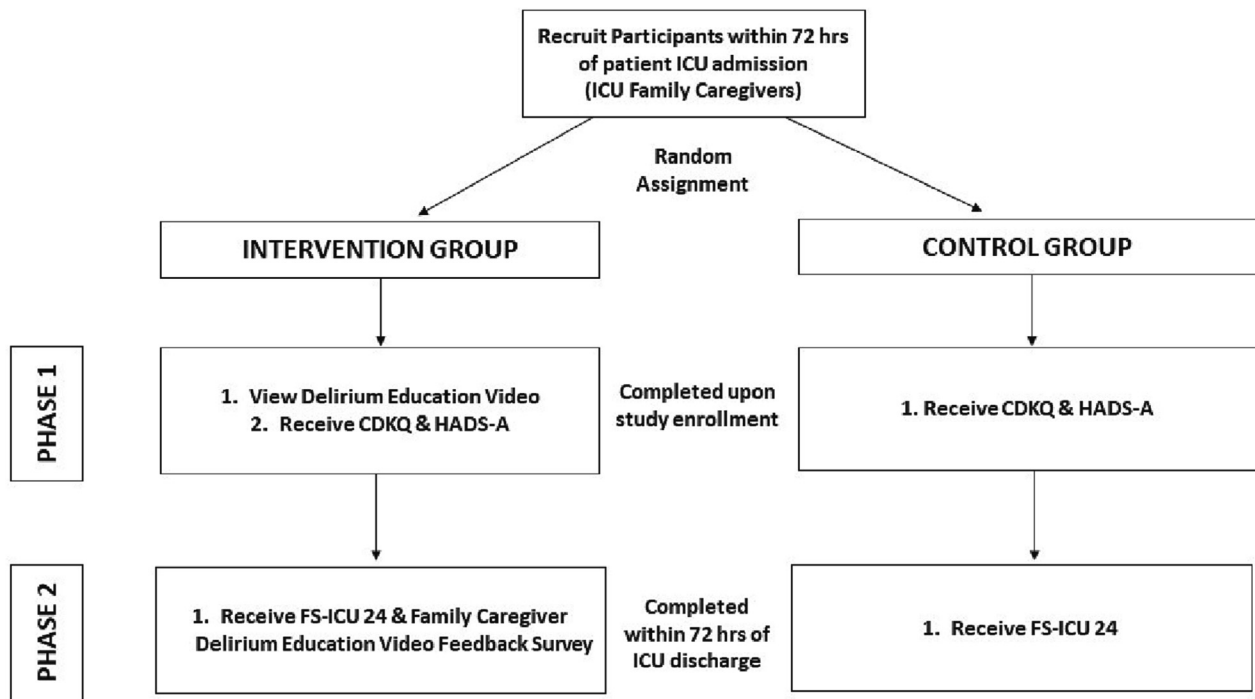


Fig. 1. Research design.

email. The intervention group received an additional Family Caregiver Delirium Education Video Feedback Survey to provide feedback on the delirium education video. In the instance where a patient had been discharged from the hospital within 72 h of ICU discharge the researcher called the family caregiver to provide the option to complete the FS-ICU 24 and the Family Caregiver Delirium Education Video Feedback Survey via phone.

2.5. Outcome measures & data collection

The primary outcome measure selected was the CDKQ, created by Bull et al. (2015) and is the first published tool to measure family caregiver knowledge of delirium. CDKQ is a 19-item questionnaire designed to assess family caregiver knowledge of delirium symptoms, risk factors, and

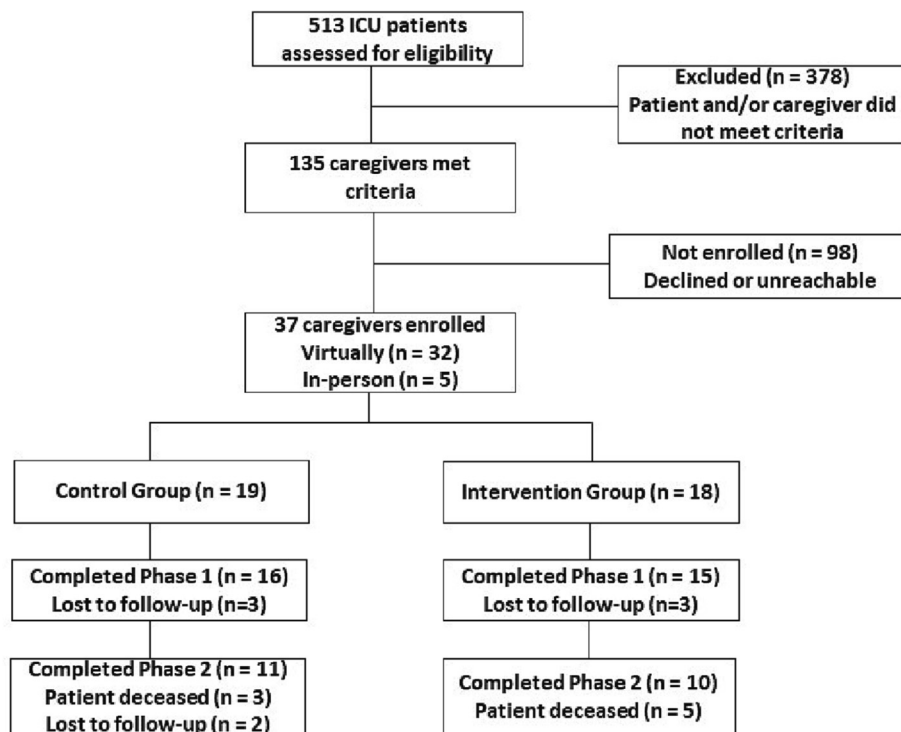


Fig. 2. Recruitment.

Table 1
Participant Demographics.

Characteristics	Control		Intervention	
	Mean (SD)		Mean (SD)	
Age	51 (12)		62 (17)	
Characteristics	%	n	%	n
Gender				
Female	94	15	67	10
Race				
White	69	11	80	12
Asian	13	2	0	0
Black	6	1	7	1
Hispanic	6	1	0	0
Marital Status				
Single	38	6	13	2
Married	56	9	87	13
Divorced	6	1	0	0
Relationship to Patient				
Child	63	10	33	5
Spouse/Partner	31	5	60	9
Sibling	6	1	7	1
Occupation				
Healthcare	19	3	13	2
Other	63	10	73	11
No Response	13	2	20	3
Income				
<\$25,000	13	2	0	0
\$25–49,000	13	2	0	0
\$50–74,999	6	1	20	3
\$75–149,000	38	6	53	8
\$150–199,000	13	2	0	0
No Response	19	3	27	4
Education				
HS Diploma	13	2	20	3
Associates	6	1	13	2
Some college	6	1	0	0
Bachelors	38	6	40	6
Masters	31	5	27	4
Time as Caregiver				
0–1 month	25	4	7	1
2–6 months	38	6	13	2
7–11 months	13	2	20	3
1–2 years	19	3	27	4
3–5 years	0	0	33	5
>5 years	6	1	0	0

appropriate actions when an older adult exhibits symptom of delirium. The CDKQ scoring is summative, with a higher score indicative of a higher knowledge of delirium. The limited existing literature establishing psychometric properties of the CDKQ revealed minor variations in internal consistency between the total score and each subsection; internal consistency for the risk subscale is 0.66, the recognition subscale is 0.72, the actions subscale is 0.49, and the total scale internal consistency is 0.76 [28].

The Family Caregiver Delirium Education Feedback Survey, created by the researchers and reviewed by the patient education committee to meet health literacy guidelines, was administered to participants in the intervention group within 72 h post-patient discharge from the ICU. The 5-item survey utilized a combination of multiple choice, Likert ratings, and one open-ended response question to allow the researcher to obtain basic information as to whether family caregivers found the resource helpful, utilized learned strategies, as well as gain feedback for improving the educational material. The survey is not a standardized assessment as it has been created for implementation with this study population as important critical end users.

Feasibility and acceptability were measured based on responses from the Family Caregiver Delirium Education Feedback Survey, specifically related to how helpful caregivers found the video, if they implemented the strategies learned, and through the open-ended responses regarding the video. Additionally, feasibility was measured based on participant enrollment. Survey study designs have a wide range of enrollment varying

Table 2
Caregiver Delirium Knowledge and Information Preferences.

	Control		Intervention	
	%	n	%	n
Heard of delirium?				
Yes	88	14	93	14
No	13	2	7	1
Know what delirium is?				
Yes	88	14	80	12
No	13	2	20	3
Experience someone with delirium?				
Yes	38	6	40	6
No	63	10	60	9
Care for someone with dementia?				
Yes	31	5	33	5
No	69	11	67	10
Want to learn about delirium?				
Yes	69	11	60	9
No	31	5	40	6
Preferred method of receiving delirium information?				
In person group class	6	1	7	1
In person individual meeting	13	2	20	3
Internet	44	7	60	9
Telephone	6	1	0	0
DVD	13	2	7	1
Newsletter	6	1	0	0
Other	13	2	7	1

based on recruitment population and methods employed. Typical enrollment ranged from as low as 10% with some studies recruiting over 50% of eligible participants [29-32]. Based on existing evidence and utilization of a mixed recruitment approach, target enrollment rate was 25%.

Information was gathered through a family caregiver sociodemographic questionnaire and review of the patient's medical record. Family caregiver socioeconomic data and instrument scores were collected and managed in REDCap. Additional measures utilized were the HADS-A and FS-ICU 24, both had strong psychometric properties and were selected based on existing supporting evidence within this population but are not discussed within the scope of this publication.

2.6. Sample size calculation

A power analysis was performed using pre-existing data on the CDKQ. The 19-item assessment was given to two groups of randomized caregivers: a control group and an intervention group. With 15 caregivers per group (30 caregivers total), there is an 85% power to detect a mean difference as small as 4 between the two groups using the assessment. This assumes a standard deviation of 3.55 of the assessment based on prior literature as well as the use of a two-sided, two-sample *t*-test with an alpha level of 0.05. As this is a feasibility study with an intervention that has never been explored a two-tailed *t*-test was utilized.

2.7. Data analysis

Descriptive statistics were conducted to characterize study participants and responses to the Family Caregiver Delirium Education Video Feedback Survey. The scores from the CDKQ, HADS-A, and FS-ICU 24 were analyzed using a paired sample *t*-test to determine statistical significance in delirium knowledge, anxiety experienced, and satisfaction with care received between the control and intervention group.

3. Results

Study enrollment occurred from October 2020 to April 2021 and ended once target sampling for each group was achieved. Power analysis indicated sampling should be 15 caregivers for each group based on the CDKQ; this was achieved.

During the recruitment period, 135 caregivers were identified as meeting criteria to participate in the study and were called or approached in

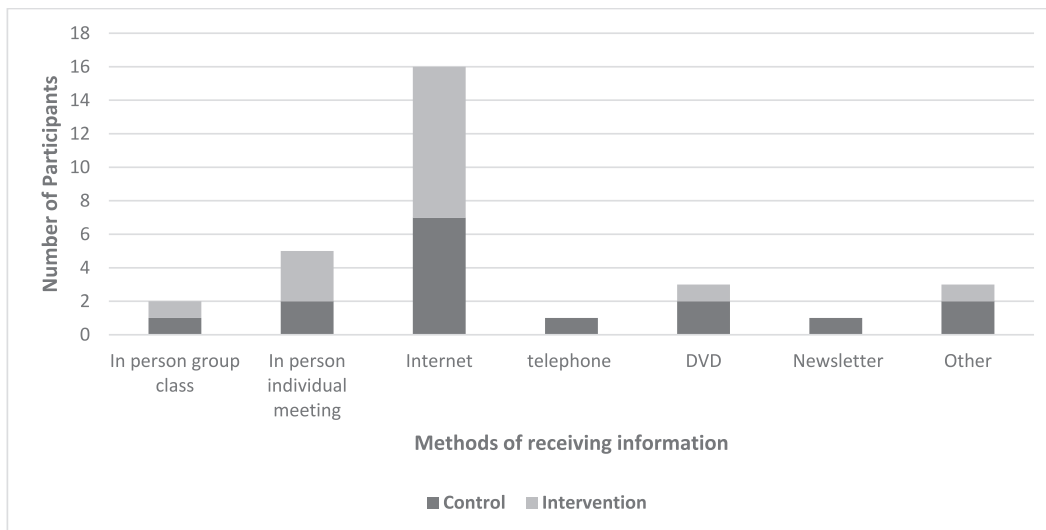


Fig. 3. Preferred method of receiving delirium information.

person at the patient's bedside in the ICU. Thirty-one completed the first phase of the study (16 control group, 15 intervention group), and 21 completed the follow-up surveys. One participant completed both time points of the study but did not respond to the HADS-A (Fig. 2).

3.1. Family caregiver demographics

Of the 31 participants who completed the first phase of the study, 16 were randomized to the control group and 15 to the intervention group. Table 1 reports the baseline characteristics of the participants. No significant differences were found in the baseline characteristics between the two groups.

The average age was 51 (SD = 12) in the control group compared to 62 years (SD = 17) in the intervention group. In the control group, 10

(63%) were the child of the patient in the ICU whereas in the intervention group nine (60%) were the spouse of the patient in the ICU. In the control group, most participants had six months or less of caregiving experience (10 [63%]); while most members in the intervention group had one to five years of experience (9 [60%]). Additional baseline characteristics were similar between groups with further details provided in Table 1.

3.2. Family caregiver delirium knowledge and information preferences

A total of 31 participants completed the questions related to prior delirium knowledge and learning preferences on the CDKQ. A higher number of participants in the control group indicated knowing what delirium is (14 [88%]; 12 [80%]) and wanting to learn about delirium (11 [69%]; 9 [60%]). Additional responses were relatively similar between groups with further details provided in Table 2.

In both groups, the most preferred method for receiving delirium information was the internet (7 [40%] control, 9 [60%] intervention; Fig. 3).

3.3. Patient demographic and clinical characteristics

Patient demographic and clinical characteristics are representative of the patient data corresponding to the 31 caregiver participants who completed the first phase of the study (16 control, 15 intervention). Specific patient data is represented in Table 3.

3.4. Feasibility of video intervention

Study findings demonstrate feasibility of implementing a caregiver education video both in-person and virtually. Study enrollment was 27%. Thirty-two out of 37 participants were virtually enrolled (Fig. 4). Six participants virtually enrolled did not complete the first phase of the study, three assigned to the control and three assigned to the intervention group.

Only two participants virtually enrolled in the intervention group opted to view the video while remaining on the phone; the others preferred completing on their own within 24 h of receiving the video link. There were two participants who viewed the video in-person. One caregiver asked if the best person to report any concerns to would be the nurse and if the family would be notified if the patient showed signs of delirium, the other participant who viewed in-person did not ask questions.

Caregivers who viewed the video completed the Family Caregiver Delirium Education Video Feedback Survey designed by the researcher within 72 h of patient discharge from the ICU. Positive feedback was received from all participants with most participants reporting being very satisfied

Table 3 Patient demographic and clinical characteristics.

Characteristics	Control		Intervention	
	Mean (SD)		Mean (SD)	
Age	71 (6)		72 (7)	
ICU Length of Stay (days)	7 (6)		7 (8)	
Hospital Length of Stay (days)	26 (36)		21 (13)	
	%	n	%	n
Gender				
Female	25	4	53	8
Cancer Diagnosis				
Genitourinary	13	2	33	5
Hematological	31	5	20	3
Gastrointestinal	25	4	13	2
Medical or Surgical				
Medical	63	10	60	9
Characteristics	%	n	%	n
ICU Admission Diagnosis				
Respiratory failure/insufficiency	19	3	40	6
Postoperative care	6	1	27	4
Sepsis	31	5	0	0
Deceased in ICU				
Yes	13	2	20	3
Admitted to ICU with Delirium				
Yes	44	7	13	2
Developed Delirium in ICU				
Yes	19	3	13	2

Note. Control Group N = 16, Intervention Group N = 15.

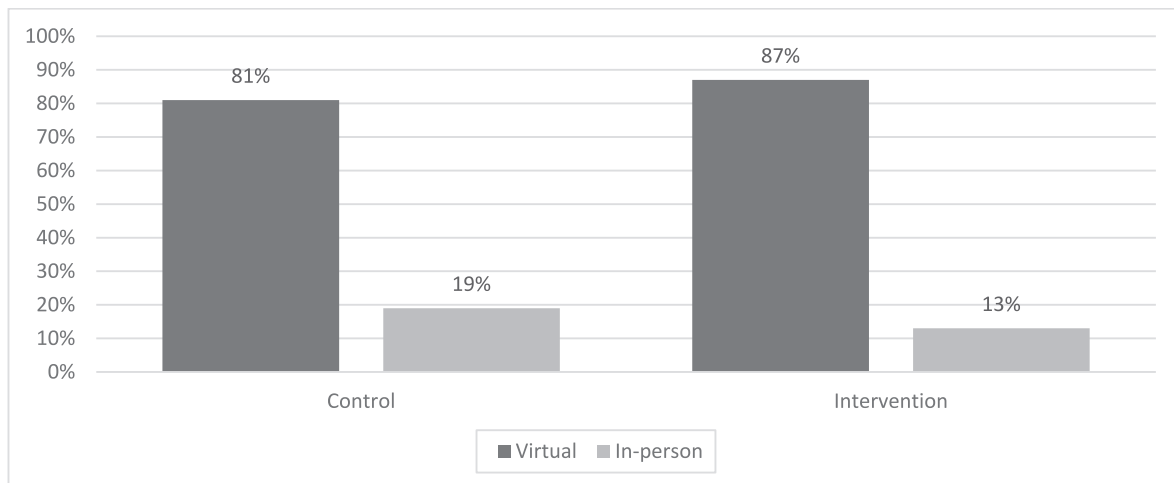


Fig. 4. Caregiver virtual versus in-person participation comparison between groups.

Table 4
Family caregiver delirium education video feedback survey responses.

Questions	%	n
1. Utilize strategies learned from video?		
Yes	70	7
2. Did you do any of these things after watching the video?		
Bring in items from home	0	0
Read to loved one	20	2
Tell loved one date/time/place often	60	6
Give eyeglasses/hearing aides	30	3
Encourage exercise/movement	70	7
Did not do any of these things	20	2

and finding the video helpful. In addition, seven (70%) out of 10 participants indicated utilizing the strategies learned from the video (Table 4). Many of the strategies included in the video were indicated as utilized with most utilized strategies being tell loved one date/time/place (6, 60%) and encouraging family member to exercise (7, 70%). The only strategy not utilized was bringing items from home (Table 4).

In addition to the Likert scale and multiple-choice questions, an open-ended question was asked for general feedback regarding the caregiver education video. Table 5 lists the comments provided by six participants; the other four participants did not provide a response. As indicated in Table 5, participants commented on finding the video to be helpful and informative. One participant commented on the impact of COVID-19 on implementation of strategies learned.

3.5. Delirium knowledge

A two sample, two-tailed t-test was performed to compare delirium knowledge in the control and intervention group, as assessed by CDKQ

Table 5
Family caregiver delirium education video feedback survey open-ended survey responses.

1. It was a good and informative video
2. It is not fair to judge as this is Covid and many things cannot happen as a result
3. I learned a lot (very helpful) thank you so much!
4. My mother was in the ICU for only about 4 days and did not seem to experience any symptoms. The video is helpful though for others who may be in a more challenging situation.
5. Great job with video
6. Every care giver should see this video to learn how to take care their love ones in a better way

scores. In comparing the overall CDKQ scores on the CDKQ there was not a significant difference in delirium knowledge between the control ($M = 12.125, SD = 2.22$) and intervention ($M = 13.6, SD = 3.2$); $t(29) = -1.49, p = .145$.

Although the total scores were not found to be significant, additional *t*-tests were run to compare scores within the three subgroups of the questionnaire. In comparison of group scores by subgroup, caregiver knowledge on patient presentation of delirium in the control group ($M = 1.94, SD = 0.5$) compared to the intervention group ($M = 2.93, SD = 1.25$) demonstrated significantly higher knowledge in the intervention group $t(29) = -1.996, p = .05$ (Table 6).

In a further sub-analysis of individual items, question number 10 ($p = .01$) within the delirium risk factors subgroup and question number 15 ($p = .04$) within the delirium presentation subgroup were found to be statistically significant (Table 7).

4. Discussion and conclusion

4.1. Discussion

The data in this study demonstrates several points for discussion including feasibility and acceptability of video education, knowledge gained in those caregivers who viewed the video compared to those who did not, and the novel approach of integrating caregivers and patients in the delirium education development process.

Results of the study demonstrate it is feasible to implement a caregiver education video about delirium both virtually and in-person to caregivers of patients in an oncology ICU. Study enrollment was aligned with similar survey study response rates even with extenuating unpredictable circumstances presented as a result of the COVID-19 pandemic [29-32]. Perhaps enrollment may be even higher outside of these circumstances. Understanding that it is feasible to provide the video intervention both virtually and in-person supports the opportunity to meet the caregiver where they are and tailor education to their preferred learning needs.

In both groups, caregivers were either the child, spouse/partner, or sibling of the patient in the ICU. Data shows that the most common caregiver is an adult child, who often takes on multigenerational caregiving and works, increasing risk for difficulty in achieving occupational balance, which is linked to health and well-being [33,34]. Allowing for on-demand virtual learning for the adult child caregiver may be more favorable compared to in-person learning because it allows for more flexibility while managing competing roles and time demands.

Additionally, caregivers who viewed the Family Caregiver Delirium Education Video intervention all provided positive feedback indicating they were very satisfied with the video and found it helpful. Those who provided

Table 6
Caregiver delirium knowledge scores by subgroup.

CDKQ Subgroup	Control	Intervention	p-value
	Mean (SD)	Mean (SD)	
1. Do you think any of the persons below might be at risk for delirium? [Risk Factors] (max score = 10)	6.62(1.5)	7.67(1.91)	0.1
2. If a family member had signs of sudden confusion, would you: [Actions] (max score = 4)	3.56 (0.5)	3 (1.25)	0.1
3. Do you think any of the older adults described below might have delirium? [Delirium Presentation] (max score = 5)	1.94(0.5)	2.93(1.25)	0.05*

Note. Control Group N = 16, Intervention Group N = 15.

* p-value ≤ .05.

open-ended feedback highlight finding the video to be a good resource whether or not their loved one had delirium and liked the video format. The information gathered from the survey supports continued use of video education which is beneficial to the family caregiver and patient. Medical staff can easily direct patients and families to view this type of educational material on hospital education channels or websites. Educational material provided in video format provides standardized information presented in a way that meets health literacy guidelines and affords greater flexibility for the caregiver and staff.

Although the total score comparison between the two groups' knowledge gained was not found to be statistically significant, additional t-tests did demonstrate significance within the delirium presentation subgroup. It is possible that with a larger caregiver sampling significance would be achieved. A hybrid multimodal approach to learning with follow-up is utilized in many current adult learning programs [35-38]. A consideration for future study would be to offer a hybrid approach to learning with integration of health care professionals providing follow-up on interventions learned either virtually or in-person based on caregiver preference and/or utilization of family mentors from the patient and family advisory council to provide support to caregivers after education is provided. Providing

additional points of contact after initial education may reinforce knowledge gained and further support integration of strategies learned.

Collaboration with PFACQ and the patient education committee to develop the video education produced a video that was well received by those who viewed it, allowed for knowledge gained, and a flexible approach to reaching caregivers either virtually or in-person. The approach used to develop the education encompasses all four tenets of patient and family care; respect and dignity, information sharing, participation, and collaboration [2]. Caregivers were active collaborators in the video development process and the primary outcome measures in the study surrounded the tenets of information sharing and participation. Utilizing this collaborative model for education development produced successful results aligned with patient- and family-centered care best practice guidelines [7].

There were a few limitations to the study. The study lacks generalizability due to the utilization of a small convenience sampling of caregivers in an oncology-specific ICU. An additional sampling limitation is that only adults fluent in English were recruited to enroll in the study. For increased generalizability this study should be conducted in a wider range of ICU units capturing a broader range of patient and caregiver populations.

Table 7
Caregiver delirium knowledge score by question.

	Control	Intervention	p-value
	Correct answer n (%)	Correct answer n (%)	
Delirium Risk Factors			
1. Older adults with an infection ^a	14(88)	14(93)	0.6
2. Older adults who are married ^b	8(50)	8(53)	0.8
3. Older adults with dementia ^a	14(88)	10(67)	0.2
4. Adults over 70 years of age ^a	12(75)	10(67)	0.6
5. Older adults with more than high school education ^b	5(31)	10(67)	0.05
6. Older adults who has had surgery ^a	11(69)	13(87)	0.3
7. Older adults not drinking enough liquid ^a	14(88)	12(80)	0.6
8. Older adults experiencing change in surroundings ^a	13(81)	14(93)	0.3
9. Older adults who are members of minority groups ^b	5(31)	9(60)	0.1
10. Older adults started on a new medication ^a	10(62)	15(100)	0.01*
Actions if a family member presented with delirium			
11. Wait a week to see if the person got better ^b	14(88)	12(80)	0.6
12. Give the person herbal tea or warm milk to help them relax ^b	12(75)	8(53)	0.2
13. Do nothing ^b	16(100)	13(87)	0.15
14. Call the doctor right away ^a	15(94)	12(80)	0.3
Delirium Presentation			
15. Older adult slowly becomes more confused over a few months, is forgetful, has trouble paying attention, and is more confused later in the day (sundown) ^b	3(19)	8(53)	0.04*
16. Older adult slowly becomes more confused over a few months, is forgetful, has trouble paying attention and later in the day (sundown) sees things that are not there ^b	2(13)	6(40)	0.09
17. Older adult suddenly becomes confused over a few days or hours, floats in and out of confusion during the day, has trouble paying attention, sees things that are not there ^a	5(31)	7(46)	0.4
18. Older adults suddenly becomes confused over a few days or hours, has trouble paying attention and sleeps more during the day ^a	11(69)	13(87)	0.3
19. Older adults becomes more confused over a few days and suddenly has trouble getting to the bathroom on time ^a	10(63)	10(67)	0.8

Note. Control Group N = 16, Intervention Group N = 15.

* p ≤ 05.

^a Correct answer is Yes.

^b Correct answer is No.

The most significant unpredictable limitation to the study was the COVID-19 pandemic, which drastically changed the landscape of the setting where the study was conducted. Several modifications to the study, including offering the study virtually and decreasing the sample size resulted from COVID-19. The decision to close recruitment once 10 participants in each group completed both phases of the study came after multiple caregivers were unable to complete the second phase due to their loved one becoming deceased in ICU as well as challenges recruiting participants with limited access to caregivers.

CIDKQ was chosen because at the time of study development there were few tools to measure delirium knowledge in family caregivers and this specific assessment had been validated for use in other settings. The population of caregivers for whom this test was validated were caregivers of patients at home, not in a hospital setting. Since the study was designed and implemented, a recent publication by the same authors was released in 2020 describing the psychometric properties for the Caregiver ICU Delirium Knowledge Questionnaire (CIDKQ), designed specifically for use with caregivers of patients in the ICU. In a review of this adapted tool, the questions posed seem more closely suited to this study. A few examples of change between the questionnaires: (a) addition of mechanical ventilation as a risk factor for delirium, (b) addition of actions to take if a family member has delirium including inform the nurse and orient the patient [39]. The examples shared were addressed within the video education tool and mirror more closely the risk factors and appropriate actions in the ICU. If this study were to be replicated in the same environment the newly developed tool should be utilized.

4.2. Innovation

This study is the first to report on outcomes related to virtual video-based delirium education for family caregivers of patients in the ICU. While there are existing patient- and family-centered care models integrating the caregiver into the design and implementation of family caregiver education, there continues to be a paucity of data exploring this partnership in the ICU to address delirium [7]. In this study, caregivers not only received education on delirium, but were integrated in video development, which aligns with the SCCM call to engage patients and family caregivers to improve patient and caregiver outcomes [7].

Additionally, results of this study highlight the benefit of offering multiple options for learning to meet the caregivers' individual needs and preferences. The ability to offer the study both virtually and in person made it possible to capture a broader range of family caregivers, particularly in a time of much uncertainty as a result of the COVID-19 pandemic. Study findings support opportunity for continued partnership with family caregivers and integration of delirium education so family caregivers may achieve optimal success in caring for their loved one while also finding self-efficacy in the responsibility of caregiving.

4.3. Conclusion

The study demonstrates knowledge gained by the group who received the education, benefits of collaborating with patients and caregivers to develop and implement a caregiver delirium education video, and feasibility of implementing video education both virtually and in-person. These findings support future research and invite consideration of further partnership with patient and family advisors to enhance caregivers' activation through various modes of education delivery that meet their learning needs.

Funding

This work was supported in part by the NIH/NCI Cancer Center Support Grant (P30 CA008748).

Declaration of Competing Interest

None.

References

- Clark AP, Guzzetta CE. A paradigm shift for patient/family-centered care in intensive care units: Bring in the family. *Crit Care Nurse*. 2017;37(2):96–9. <https://doi.org/10.4037/ccn2017142>.
- Anderson AC, Akre E, Chen J. Exploring national trends of patient- and family-centered care among US children. *J Child Health Care*. 2018;23(2). <https://doi.org/10.1177/1367493518786015>.
- Cannon S. Family-centered care in the critical care setting: Is it best practice? *Dimens Crit Care Nurs*. 2011;30(5):241–5. <https://doi.org/10.1097/DCC.0b013e3182276f9a>.
- Howrey BT, Thompson BL, Borkan J, Kennedy LB, Hughes LS, Johnson BH, et al. Partnering with patients, families, and communities. *Fam Med*. 2015 Sep;47(8):604–11. PMID: 26382118.
- Boltz M, Chippendale T, Resnick B, Galvin J. Anxiety in family caregivers of hospitalized persons with dementia: Contributing factors and responses. *Alzheimer Dis Assoc Disord*. 2015;29(3):236–41. <https://doi.org/10.1097/WAD.000000000000072>.
- Boltz M, Chippendale T, Resnick B, Galvin J. Testing family-centered, function-focused care in hospitalized persons with dementia. *Neurodegen Dis Manag*. 2015;5(3):203–15. <https://doi.org/10.2217/nmt.15.10>.
- Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med*. 2017;45(1):103–28. <https://doi.org/10.1097/CCM.0000000000002169>.
- American Psychiatric Association. DSM-5 classification. <https://www.psychiatry.org/psychiatrists/practice/dsm/updates-to-dsm-5/coding-updates/2016-coding-updates;2016>.
- McFarling U. Hospitals struggle to address terrifying and long-lasting 'ICU delirium'. *STATnews.com*. Boston, MA: Boston Globe Media; 2016.
- Carbone MK, Gugliucci MR. Delirium and the family caregiver: The need for evidence-based education interventions. *Gerontologist*. 2015;55(3):345–52. <https://doi.org/10.1093/geront/gnu035>.
- Asa AH, Wicks MN, Umberger RA. Family caregivers' experience of patients with delirium in critical care units: A state-of-the-science integrative review. *Am J Crit Care*. 2021;30(6):471–8. <https://doi.org/10.4037/ajcc2021394>.
- Maldonado JR. Neuropathogenesis of delirium: Review of current etiologic theories and common pathways. *Am J Geriatr Psychiatry*. 2013;21(12):1190–222. <https://doi.org/10.1016/j.jagp.2013.09.005>.
- Alvarez EA, Garrido MA, Tobar EA, Prieto SA, Vergara SO, Briceno CD, et al. Occupational therapy for delirium management in elderly patients without mechanical ventilation in an intensive care unit: A pilot randomized clinical trial. *J Crit Care*. 2017;37:85–90. <https://doi.org/10.1016/j.jcrrc.2016.09.002>.
- Hshieh TT, Saczynski J, Gou RY, Marcantonio E, Jones RN, Schmitt E, et al. Trajectory of functional recovery after postoperative delirium in elective surgery. *Ann Surg*. 2016;265(4):647–53. <https://doi.org/10.1097/SLA.0000000000001952>.
- Johansson YA, Bergh I, Ericsson I, et al. Delirium in older hospitalized patients—signs and actions: A retrospective patient record review. *BMC Geriatr*. 2018;18:43. <https://doi.org/10.1186/s12877-018-0731-5>.
- Lawlor PG, Bush SH. Delirium in patients with cancer: Assessment, impact, mechanisms and management. *Nat Rev Clin Oncol*. 2015;12(2):77–92. <https://doi.org/10.1038/nrclinonc.2014.147>.
- Bull MJ, Boaz L, Jermé M. Educating family caregivers for older adults about delirium: A systematic review. *Worldviews Evid Based Nurs*. 2016;13(3):232–40. <https://doi.org/10.1111/wvn.12154>.
- Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs S. Caregiver burden: A clinical review. *JAMA*. 2014;311(10):1052–60. <https://doi.org/10.1001/jama.2014.304>.
- Bull MJ, et al. Preparing family caregivers to recognize delirium symptoms in older adults after elective hip or knee arthroplasty. *J Am Geriatr Soc*. 2017;65(1):e13–7. <https://doi.org/10.1111/jgs.14535>.
- Whittamore KH, Goldberg SE, Bradshaw LE, Harwood RH. Factors associated with family caregiver dissatisfaction with acute hospital care of older cognitively impaired relatives. *J Am Geriatr Soc*. 2014;62(12):2252–60. <https://doi.org/10.1111/jgs.13147>.
- Lam M, Choi M, Lam HR, Agarwal A, Chow R, Chow S, et al. Use of multimedia in patient and caregiver education for cancer pain management: A literature review. *Ann Palliat Med*. 2017;6(1):66–72. <https://doi.org/10.21037/apm.2016.11.06>.
- Bakas T, Clark PC, Kelly-Hayes M, King RB, Lutz BJ, Miller EL, et al. Evidence for stroke family caregiver and dyad interventions: A statement for healthcare professionals from the American Heart Association and American Stroke Association. *Stroke*. 2014;45(9):2836–52. <https://doi.org/10.1161/STR.0000000000000033>.
- Paulson C, Monroe T, McDougall G, Fick D. A family-focused delirium educational initiative with practice and research implications. *Gerontol Geriatr Educ*. 2016;37(1):4–11. <https://doi.org/10.1080/02701960.2015.1031896>.
- Bull MJ, Boaz L, Sjostedt JM. Family caregivers' knowledge of delirium and preferred modalities for receipt of information. *J Appl Gerontol*. 2016;35(7):744–58. <https://doi.org/10.1177/0733464814535484>.
- Ely EW. The ABCDEF bundle: Science and philosophy of how ICU liberation serves patients and families. *Crit Care Med*. 2017;45(2):321–30. <https://doi.org/10.1097/CCM.0000000000002175>.
- Rosenbloom DA, Fick DM. Nurse/family caregiver intervention for delirium increases delirium knowledge and improves attitudes toward partnership. *Geriatr Nurs*. 2014;35(3):175–81. <https://doi.org/10.1016/j.gerinurse.2013.12.004>.
- Rosenbloom-Brunton DA, Henneman EA, Inouye SK. Feasibility of family participation in a delirium prevention program for hospitalized older adults. *J Gerontol Nurs*. 2010;36(9):22–33. <https://doi.org/10.3928/00989134-20100330-02>.
- Bull MJ, Boaz L, Maadooliat M, Hagle ME, Gettrust L, Greene MT, et al. Psychometric properties of the family caregiver delirium knowledge questionnaire. *Res Gerontol Nurs*. 2015;8(4):198–207. <https://doi.org/10.3928/19404921-20150409-01>.

- [29] Blumenberg C, Menezes AM, Goncalves H, Assuncao MC, Wehrmeister FC, Barros AJD. How different online recruitment methods impact on recruitment rates for the web-based coortesnaweb project: a randomised trial. *BMC Med Res Methodol.* 2019;19(1). <https://doi.org/10.1186/s12874-019-0767-z>.
- [30] Booker QS, Austin JD, Balasubramanian BA. Survey strategies to increase participant response rates in primary care research studies. *Fam Pract.* 2021;38(5):699–702. <https://doi.org/10.1093/fampra/cmab070>.
- [31] Mathews M, Parast L, Tolpadi A, Elliott M, Flow-Delwiche E, Becker K. Methods for improving response rates in an emergency department setting – A randomized feasibility study. *Surv Pract.* 2019;12(1):1–14. <https://doi.org/10.29115/SP-2019-0007>.
- [32] Moseson H, Kumar S, Juusola JL. Comparison of study samples recruited with virtual versus traditional recruitment methods. *Contemp Clin Trials Commun.* 2020; 19:100590. <https://doi.org/10.1016/j.conctc.2020.100590>.
- [33] Evans KL, Girdler SJ, Falkmer T, Richmond JE, Wagman P, Millsteed J, et al. Viewpoints of working sandwich generation women and occupational therapists on role balance strategies. *Scand J Occup Ther.* 2017;24(5):366–82. <https://doi.org/10.1080/11038128.2016.1250814>.
- [34] National Academies of Sciences Engineering and Medicine Committee on Family Caregiving for Older Adults. *Families caring for an aging America.* Washington, DC: The National Academies Press; 2016..
- [35] Kontos E, Blake KD, Chou WS, Prestin A. Predictors of eHealth usage: Insights on the digital divide from the health information national trends survey 2012. *J Med Internet Res.* 2014;6(7):e172. <https://doi.org/10.2196/jmir.3117>.
- [36] Lindeman DA, Kim KK, Gladstone C, Apesoa-Varano EC. Technology and caregiving: Emerging interventions and directions for research. *Gerontologist.* 2020;60(Supplement_1):S41–9. <https://doi.org/10.1093/geront/gnz178>.
- [37] Lightfoot E, Yun H, Moone R, Otis J, Suleiman K, Turck K, et al. Changes to family caregiving of older adults and adults with disabilities during COVID-19. *Gerontol Geriatr Med.* 2021;7. <https://doi.org/10.1177/23337214211002404>. 23337214211002404.
- [38] Cravello L, Martini E, Viti N, Campanello C, Assogna F, Perotta D. Effectiveness of a family support intervention on caregiving burden in family of elderly patients with cognitive decline after the COVID-19 lockdown. *Front Psych.* 2021;12:590104. <https://doi.org/10.3389/fpsy.2021.590104>.
- [39] Krewulak KD, Bull MJ, Ely EW, Stelfox HT, Fiest KM. Psychometric evaluation of the family caregiver ICU delirium knowledge questionnaire. *BMC Health Serv Res.* 2020; 20(1). <https://doi.org/10.1186/s12913-020-4892-5>.