

The effects of advance care planning on the  
quality of life in elderly patients:  
A literature review

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## ABSTRAKT

Lovisenberg diakonale høgskole  
Dato: 26.08.2023

Tittel: Effekter av forhåndssamtale hos eldre pasienters livskvalitet

### Bakgrunn

#### Del 1

Forhåndssamtale har fått mye oppmerksomhet som en løsning for pasient-sentrert omsorg og respekt for pasientenes autonomi hos eldre pasienter. Imidlertid forblir oppfølgingen av forhåndssamtale tross for dokumenterte positive effekter på flere utfallsmål.

#### Del 2

Pasientrapporterte resultater brukes ofte i studier om livskvalitet og kan påvirke gyldigheten av datainnsamlingen, og dermed påvirke syntesen av resultater.

### Hensikt

#### Del 1

Å evaluere og syntetisere effektene av forhåndssamtale på livskvaliteten hos eldre pasienter.

#### Del 2

Å identifisere utfordringene ved bruk av pasientrapporterte resultater i studier om livskvalitet hos eldre pasienter.

### Metode

#### Del 1

Denne litteratur oversikten er rapportert i tråd med PRISMA-sjekklisten. Forfatteren søkte systematisk gjennom CINAHL, MEDLINE og PSYCHINFO databasene. Søkeresultatene ble gjennomgått og vurdert kritisk av forfatteren. Effektene av forhåndssamtale på livskvaliteten hos eldre pasienter ble oppsummert og presentert i en narrativ syntese.

#### Del 2

Bruken av pasientrapporterte resultater kan ha problemer med gyldighet og nøyaktighet. Disse utfordringene ble identifisert i forbindelse med studier om livskvalitet hos eldre pasienter og diskutert i lys av relevant litteratur.

### Resultat

#### Del 1

Denne gjennomgangen inkluderte to randomiserte kontrollerte studier, to kvasi-eksperimentelle studier og en ikke-randomiserte studie med totalt 1110 deltakere. Tre studier viste statistiske signifikant sammenheng mellom forhåndssamtale og livskvalitet hos eldre pasienter.

#### Del 2

Flertallet av studiene har tatt tiltak for enten å teste sine respektive instrumenter i pilotstudier for å tilpasse dem til den eldre befolkningen, eller å teste deres tverrkulturelle gyldighet.

### Konklusjon

#### Del 1

Det er utfordrende å konkludere med om forhåndssamtale har positive effekter på livskvaliteten til eldre pasienter, basert på de motstridende resultatene mellom studiene.

#### Del 2

Bruken av pasientrapporterte resultater er essensiell for å måle livskvalitet, men instrumentene bør involvere eldre pasienter i å identifisere utfallsmål, ta hensyn til deres svekkede kognitive helsetilstand og tverrkulturelle forskjeller.

**Nøkkelord: Forhåndssamtale; Livskvalitet; Eldre**

## ABSTRACT

Lovisenberg Diaconal University College  
Date: 26.08.2023

Title: The effects of advance care planning on the quality of life in elderly patients

### Background

#### Part 1

Advance care planning has earned much attention as a solution to patient-centred care and respecting elderly patients' autonomy. However, uptake remains low despite documented positive effects on several outcome measures.

#### Part 2

Patient-reported outcomes are often used in quality-of-life studies and can affect the validity of data collection thereby influencing the synthesis of results.

### Aim

#### Part 1

To evaluate and synthesize the effects of advance care planning on the quality of life of elderly patients.

#### Part 2

To identify the challenges in using patient-reported outcomes in quality-of-life studies on elderly patients.

### Methods

#### Part 1

This literature review is reported in accordance with the PRISMA checklist. The author systematically searched CINAHL, MEDLINE and PSYCHINFO databases. Search results were reviewed and critically assessed by the author. The effects of the advance care planning intervention on the quality of life in elderly patients were summarized and presented in narrative synthesis.

#### Part 2

The use of patient-reported outcomes can have issues concerning validity. These challenges were identified in connection with quality-of-life studies in elderly patients and discussed against relevant literature.

### Result

#### Part 1

This review included two RCTs, two quasi-experimental studies, and one non-randomized study with a total of 1110 participants. Three studies showed statistically significant association between advance care planning and quality-of-life.

#### Part 2

The majority of the studies has taken measures to pilot-test their respective instruments to adapt to the elderly population and to test their cross-cultural validity.

### Conclusion

#### Part 1

It is challenging to conclude whether advance care planning has positive effects on the quality-of-life in elderly patients based on the conflicting results between studies.

#### Part 2

The use of patient-reported outcomes is essential in measuring quality-of-life, but instruments should involve elderly patients in identifying outcome measures, consider their deteriorating cognitive states and cross-cultural differences.

**Key Words: Advance Care Planning; Quality of Life; Elderly**

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# 1. Literature review article

**A literature review article reported in accordance with PRISMA and author guidelines for International Journal of Nursing studies.**

## **Abstract**

**Background:** Elderly patients experience low quality-of-life due to reduced physical and cognitive function, frailty and multimorbidity. Advance care planning has received much attention as a promising solution for respecting patients' autonomy and ensuring patient-centred care thus, improving their quality-of-life. Previous studies have focused on several outcome measures in diagnostic specific studies and in specialized and tertiary care settings. Reviews that investigate quality-of-life in primary and community-based care are required.

**Objective:** This literature review aimed to evaluate the effects of the advance care planning intervention on the quality-of-life of elderly patients in community-based and primary health care.

**Methods:** This literature review utilized the framework of doing a literature review by Booth et al. (2022) and was reported in accordance with the PRISMA 2020 statement. The studies included were identified through a systematic search in CINAHL, MEDLINE and PSYCHINFO. Quantitative studies, including RCTS, quasi-experimental studies, and non-RCTs that explored ACP intervention effects on the quality of life in elderly patients in community-based and primary health care were included. The search results were critically reviewed and assessed by the author. The outcome measure quality-of-life was summarized and presented in narrative synthesis.

**Results:** Five studies were included with a total of 1110 participants. There was conflicting evidence regarding the effectiveness of advance care planning on the quality-of-life outcome measure. Advance care planning interventions varied between studies using different instruments in gathering self-report data on the outcome quality-of-life.

**Conclusion:** To conclude whether the advance care planning intervention has a direct effect on the quality of life in elderly patients is challenging because of conflicting findings between the included studies, therefore, it is uncertain to conclude its clinical relevance. Future studies are needed to explore advance care planning discussions with the elderly population taking into consideration the methodological implementation and timing of interventions.

**Key Words:** Advance Care Planning, Quality-of-life, Elderly

## **1. Introduction**

According to the World Health Organization (WHO), by the year 2030, one in six people worldwide will be aged 60 years and over. The ageing population is characterized by the emergence of several complex health states such as multiple health conditions with consequences such as frailty, falls and delirium (WHO, 2022). These worldwide demographic changes lead to increased numbers of care dependent and chronically ill elderly (Schnakenberg et al., 2020).

Several older adults are experiencing cognitive impairment, frailty, and comorbidities which results in increased incidence of adverse outcomes such as hospitalisation, increased health care expenditure and poorer quality-of-life (QoL) (Weathers, O'Caomh, et al., 2016). Multimorbidity are highly prevalent in older adults and has direct adverse effects on one's health status and QoL (Grembowski et al., 2014) . For example, a literature study on multimorbidity among the elderly identified functional decline, disability, high health care costs and poor QoL as common consequences (Marengoni et al., 2011). In addition, a more recent study confirms earlier studies showing evidence on association between multimorbidity and poor QoL, in both physical and mental health (Makovski et al., 2019). Studies on multimorbid elderly patients identified independence, daily functioning, and a good QoL as more important than life expectancy. Thus, the elderly population is likely to experience increasing symptoms and a decrease in QoL for several years prior to death (Cleary, 2016).

Advance Care Planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care (Sudore et al., 2017). ACP involves discussions between patients, families, and healthcare professionals on future healthcare decisions, in anticipation of impairment in decision-making capacity, which improves satisfaction of end-of-life care while respecting patient autonomy (Weathers, O'Caomh, et al., 2016). The concept of ACP has been increasingly important for patients to document their future treatment preferences thus extending the patient's autonomy to a phase in life where he or she becomes incapacitated (Lum et al., 2015; Schnakenberg et al., 2020). This process commonly results in choosing and preparing another trusted person or persons to make medical decisions in the event the patient can no longer make his or her own decisions (Sudore et al., 2017). The goal of ACP is to

ensure goal concordant care near the end-of-life for patients who lack decisional capacity (Morrison et al, 2021). ACP highlights greater autonomy, choice and control, respect of the person's human rights, enabling a sense of retaining control, self-determination, and empowerment (Gold Standards Framework, 2022).

Older adults in primary health care and community-based settings, like home-based care or nursing homes, are important clients of ACP (E.-J. Park et al., 2021). This is supported by a systematic review which recommends that early ACP interventions in nursing homes while residents still have the cognitive capacity to state their wishes and preferences are crucial (Weathers et al., 2016). ACP is important for those who are able to make decisions now, to plan and to live life as fully as possible until they die (National Goal Standards Framework, 2022). Considering the beneficial effects of ACP on documentation of end-of-life care preferences, implementation of ACP intervention is recommended in nursing home or clinical care settings caring for older adults (Ng et al., 2022).

Quality-of-life (QoL) and health-related quality of life (HRQOL) have been commonly used as outcome measures in healthcare. The underlying reason for measuring QoL is to ensure that evaluations focus on the patient rather than the disease (Leegaard et al., 2018). Moreover, QoL is a meaningful measure in the evaluation of health care services and patient-reported outcomes (Makovski et al., 2019). It is essential to measure psychometrically valid patient-reported outcomes, including the presence and severity of symptoms and HRQOL (Morrison et al., 2021). Because of a wide variety of outcome measures in studies of ACP, a Delphi panel came up with a consensus of four major outcome domains, one of which is self-rated QoL under the healthcare domain (Sudore et al., 2018). ACP has been shown to have positive effects on QoL in patients suffering from heart failure (Schichtel et al., 2020). Another study showed that patients with gastrointestinal cancer maintained a good QoL despite their poor prognosis through early ACP intervention. (Canny et al., 2022).

An overview of systematic reviews on ACP with no restrictions on setting, study design and population showed that majority of ACP studies investigated ACP in connection with end-of-life care and documentation of patient-preferences for future treatment (Jimenez et al., 2019). A scoping review on advance care planning outcomes showed most ACP intervention studies were done in outpatient settings and positive results in outcome measures such as patient readiness, communication, and documentation (McMahan et al., 2021). Literature studies on

evaluating ACP effectiveness on patient outcomes on elderly patients in community and primary care settings are needed.

The present study will systematically evaluate and synthesize the effects of ACP on the QoL of elderly patients in primary health care and community-based settings including home-based and nursing home residents, as well as appraise the methodological quality of the studies included. As of date, this has not previously been done.

## **2. Methods**

This study was conducted as a literature review including narrative synthesis of the included studies utilizing the framework by Booth et al. (2022) and is presented in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines (Page et al., 2021).

### **2.1 Search strategy**

A comprehensive search of three databases: CINAHL, Medline, and PsychInfo was conducted for this review. The search for the primary studies included in the review were guided by the PICO criteria (For details, see Supplementary Table 1). Search terms included (advance care planning AND elderly OR aged OR older people OR frail elderly OR geriatric OR ageing or senior\* AND quality of life OR qol OR health-related quality of life OR hrqol) (For more details, see Supplementary Table 2). Search for primary health care and community-based settings including home-based or nursing homes were done manually by the researcher. Reference lists of previously published reviews from the abovementioned databases was gone through manually by the researcher. Search limiters were only set on English and Norwegian languages and year from 2012 until February 17, 2023.

### **2.2 Eligibility criteria**

Studies were included to the present review if the primary study were (1) quantitative studies, (2) used advance care planning interventions, (3) were conducted in the primary health care



and community-based settings, including home-based care and nursing home care, (4) reported quality of life as an outcome, and (5) were published in the English or Norwegian languages. Studies that included ACP as a part of other intervention approaches such as palliative care were excluded. Qualitative studies, mixed-methods studies, systematic reviews and meta-analyses, editorials, grey literature, unpublished literature, and studies that included ACP interventions outside the community setting such as hospital and emergency settings were excluded. Finally, the outcome of interest, namely quality of life had to be self-reported by the patients themselves and not by patient relatives or health care professionals.

Community-based settings in this study referred to any type of health care providers excluding hospitals for in-patients (Organisation for Economic Co-operation and Development, Eurostat and World Health Organisation, 2017). Definitions for elderly was not pre-determined but accepted as defined by each article.

### **2.3 Study selection**

The pooled articles from the databases were imported to EndNote and categorised under which database they were retrieved from. They were then imported to Rayyan where duplicates were removed. Rayyan shows a 100% statistical probability to identify duplicates. Titles and abstracts were assessed independently against the inclusion criteria. A full text of each relevant study was retrieved, read, and reread for eligibility.

### **2.4 Data extraction**

The data extraction was done using the Joanna Briggs Institute (JBI) System for the Unified Management of the Assessment and Review of Information (SUMARI) data extraction format (Munn et al., 2019). The following data were extracted: family name of the first author, year of article publication, country of origin, study design and aim of the study, research setting, participants, sample size, gender, mean age and inclusion criteria, ACP intervention, assessment time-points and study's quality of life outcome measures.

## **2.5 Quality assessment**

The Joanna Briggs Institute (JBI) critical appraisal for RCTs and quasi-experimental studies were used (Barker et al., 2023) and ROBINS-I for the non-randomized study (Morgan et al., 2018). All the studies were critically reviewed and the results for the appraisal are respectively summarized in Supplementary material tables 4a, 4b, and 4c. The overall score for every item was presented in percentage (Barker et al., 2023).

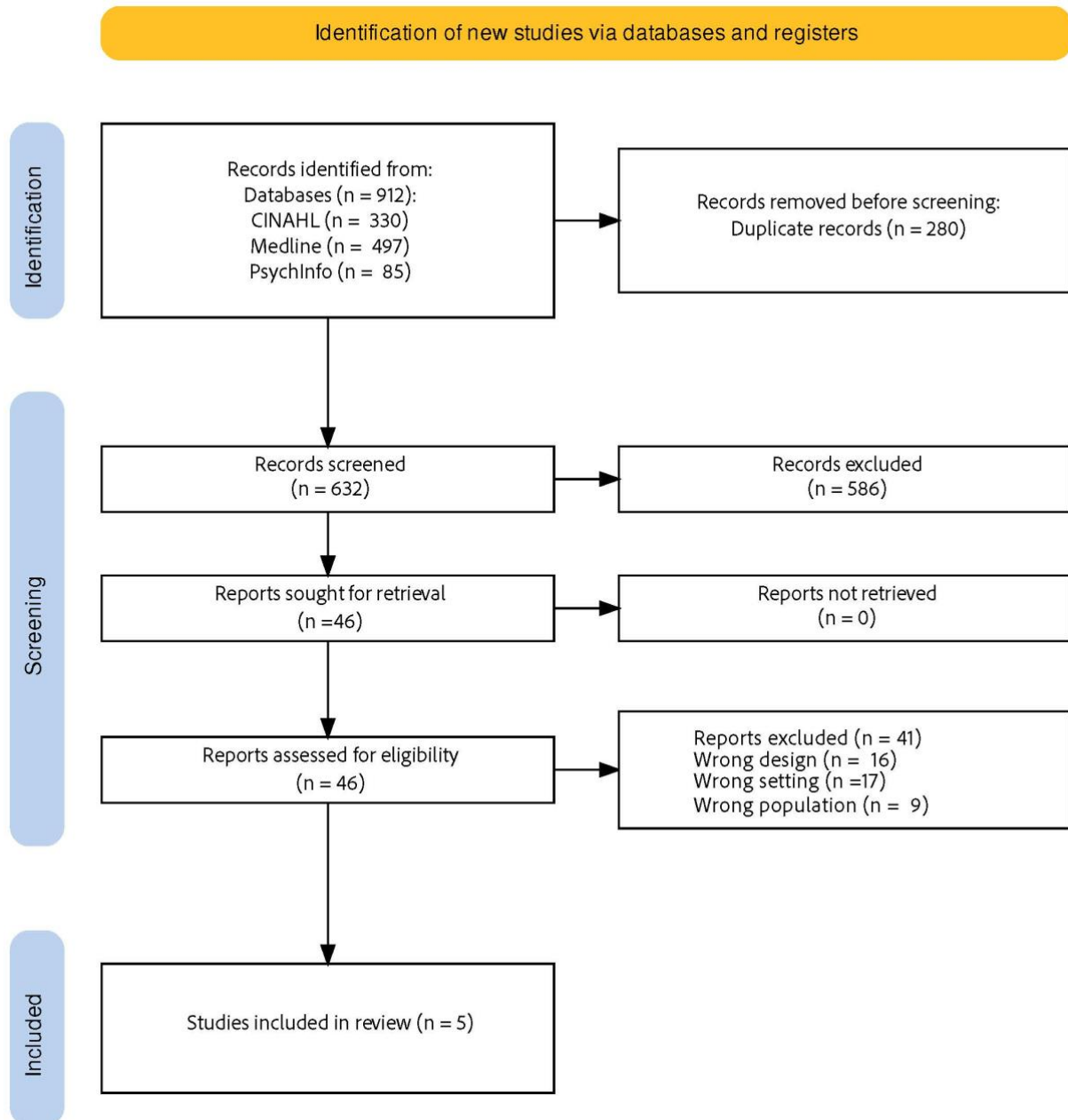
## **2.6 Data analyses**

This study used a narrative synthesis approach to analyse the results and included articles with texts and tables (Booth et al., 2022; Aveyard et al., 2021). In addition, in evaluating the effectiveness of the ACP intervention on the outcome measure quality-of-life, results were considered effective with statistical significance set at p-values < .05.

## **3. Results**

### **3.1 Identification of studies**

Of the 912 articles identified, 280 were duplicates. The remaining 632 articles were screened by going through the titles and abstracts against the inclusion and exclusion criteria. Forty-six articles were sought for retrieval and assessed in full text. Finally, five primary articles were included in the present review. The literature search results and reason for exclusion are described in PRISMA flow diagram (Figure 1) below.



**Figure 1:** PRISMA flow diagram for selection of study

### 3.2 Study Characteristics

Of the five studies included, one study was from China (Deng et al., 2020), one from Japan (Okada et al., 2022), one from Hongkong (Chan et al., 2021), one from The Netherlands (Overbeek et al., 2019), and one from USA (Lum et al., 2018). The five studies included 1110 participants. Two studies had participants from 60 years of age (Deng et al., 2020, Lum et al.,

2018), one from the age of 65 years (Okada et al., 2022), and one from 75 years (Overbeek et al., 2018). Average age for the participants at baseline were 79,5.

Of the included studies, two studies were randomized controlled trials (RCTs) (Lum et al., 2018; Overbeek et al., 2018), two had quasi-experimental design (Chan et al., 2021; Deng et al., 2020), and one was a non-randomized cohort-type study (Okada et al., 2022).

Two studies had participants from nursing homes (Chan et al., 2021; Deng et al., 2020). One study recruited participants from both nursing homes and home care patients (Overbeek et al., 2018). One study had primary health care patients (Lum et al., 2018), and one had participants chosen from an online based pool of participants who met the study's research criteria (Okada et al., 2022).

Three studies had a one-on-one direct discussion with a nurse who had trained to conduct ACP discussion (Deng et al., 2020, Okada et al., 2022, Overbeek et al., 2018). One study (Chan et al., 2021) used a group discussion with a social worker. And one study (Lum et al., 2018) had participants take an internet-based ACP guide in designated test centres.

One study (Overbeek et al., 2018) had quality of life as a secondary outcome and used Short Form-12 (SF-12) questionnaire. Two studies (Chan et al., 2021, Deng et al., 2020) used the same instrument Quality of Life Concerns in End-of-Life (QOLC-E) and modified Quality-of-Life Concerns in End-of-Life (mQOLC-E) that measures physical, psychological, emotional, relational, and existential aspects that influences QoL, both studies had QoL as a primary outcome. One study (Okada et al., 2022) had QoL as a primary outcome and used Comprehensive Quality-of-Life Outcome (CoQoLo) scale to evaluate what constitutes a good death.

All five studies (Chan et al., 2021; Deng et al., 2020; Lum et al., 2018; Okada et al., 2022; Overbeek et al., 2018) had Advance Directive (AD) documentation as a goal. Three studies (Lum et al., 2018, Okada et al., 2022; Overbeek et al., 2018) had ACP engagement as a result. Four studies (Chan et al., 2021; Deng et al., 2020; Lum et al., 2018; Okada et al., 2022) had QoL embedded in end-of-life care, and one study (Overbeek et al., 2018) did not have this correlation.

### **3.3 Results on the quality-of-life outcome measure**

Three studies (Deng et al., 2020; Lum et al., 2018; Okada et al., 2022) showed statistically significant correlation between ACP interventions and QoL. The study by Deng et al. (2020) had three outcome measurements where the first was done as a baseline assessment and two assessment measurements post ACP intervention using the mQOLC-E Questionnaire which covered six dimensions including physical comfort, negative emotions, existential distress, value of life, and support and food-related concerns. There was a significant difference in the care and support ( $p = 0.016$ ) subscale and value of life subscale ( $p = 0.012$ ). The study by Okada et al. (2020) administered the CoQoLo scale at two time-points: pre-intervention and 6 months post-intervention where results showed a statistically significant association was detected between QoL and ACP discussions ( $p = 0.01$ ). The study by Lum et al. (2018) which used the Quality-of-Life subscale which included acceptable health states and care desired at the end of life made measurements at baseline, one week, three months and 6 months after showed scores increasing significantly over time for the QoL action subscale ( $p \leq 0.005$ ).

Two studies (Chan et al., 2021; Overbeek et al., 2018) showed no statistical correlation between ACP and QoL. The study by Chan et al. (2021) completed that QOLC-E at two points: one week before and one week after the ACP group intervention. There were seven weeks between T0 and T1. There was no statistically significant improvement in QOLC-E sub-scores following the ACP intervention ( $p > 0.005$ ). The study by Overbeek et al. (2018) used the generic SF-12 Health Survey to measure QoL 12 months after the ACP intervention. Results showed no significant difference in both the Physical Component Score ( $p = 0.98$ ) and Mental Component Score ( $p = 0.71$ ) of the SF-12.

### **3.4 Reporting biases**

The risk of bias was consistently low for all five included studies. A summary of risk of bias is presented in Supplementary materials Table 3. For the two RCTs, the study by Overbeek et al. (2021) described that the expected loss to follow-up was not accounted for in their power calculations but it was unlikely that it affected the study given the small size of the difference. In addition, outcome assessors could not be blinded to participant allocation because of the

nature of the follow-up assessment. The second RCT by Lum et al., 2018 where participants completed an online ACP survey, allocation to between AD (Advance Directive)-only and PREPARE + AD group were not concealed.

For the quasi-experimental studies, the study by Chan et al. (2021) only had one measurement of outcomes post-intervention. For the study by Deng et al. (2020), convenience sampling and single blinding were employed which may have decreased its external validity and potentially bias. Lastly the non-randomized study (Okada et al.,2022) showed lack of random assignment.

Thus, this review should be interpreted in consideration of several limitations as well as limitations from the individual studies included.

Table 1. Literature matrix

Author, year, country	Study design, aim	Setting	Participants (number; gender; mean age)	Intervention	Assessment time-point	Outcome measures	Results
(Chan et al., 2021) Hong Kong	Quasi-experimental study  To examine the effects of an ACP group developed by social workers for frail older adults in residential care homes of Hong Kong	14 residential care homes which were invited by the Society for the Promotion of Hospice Care (SPHC), a non-government organisation (NGO) in Hong Kong, as part of their initiative to promote ACP for older adults in Hong Kong.	N=117; n=59 intervention and n=58 control  female 94 (80.3 %), mean age 86.45, (SD 8.08)  Inclusion criteria: Able to communicate in Cantonese and be cognitively and mentally competent enough to complete a questionnaire. Those who were mentally and emotionally unfit to join the study were excluded.	A community-based group ACP approach  The intervention led by a social worker, had six sessions which was offered weekly in the homes, for 1.5 hr each time, in a closed group of 6 to 8 participants.	Participants were to complete a questionnaire at two points: T0 (1 week before the ACP group intervention) and T1 (1 week after the ACP group intervention). There were 7 weeks between T0 and T1.	Quality of life concerns (QOLC) measured by the Modified Quality of Life in the End-of-Life Questionnaire (QOLC-E).	No significant improvement in QOLC-E sub-scores following the ACP intervention (p>0.05)
(Deng et al., 2020) China	Quasi-experimental design  To evaluate the effectiveness of a modified ACP intervention in certainty of end-	Two nursing homes in Huzhou city, Zhejiang Province, China	N=148; n=74 intervention; n=74 control  female 42 (56,8%), mean age 84.3 +- 5.67  Inclusion criteria:	A modified ACP intervention based on the conceptual change model. Three monthly 1-hour face-to-face interviews in each participant's room by a research nurse who had 3 years' experience in	Three outcome measurements were made; T0 as a baseline assessment, T1 as an immediate assessment after intervention, T2 as a 2-month	Quality of life; The modified quality-of-life Concerns in the End-of-Life Questionnaire (mQOLC-E) was used.	There was a significant difference in the care and support subscale of mQOLC-E (p=0.016) and the value of

	of-life care, preferences for end-of-life care, quality of life concerns, and healthcare utilization among frail older people		Residents 60 years and over, able to communicate in Mandarin, cognitive competence, and frail older adults.  Older adults who were diagnosed with psychiatric or cognitive problems or had communication difficulties (such as hearing loss, aphasia, or unable to understand Mandarin) were excluded.	an oncology department and had attended psychological counselling and ACP training courses.	assessment after the intervention.		life subscale (p=0.012). There was a time and an interaction effect on existential distress at T1 and physical discomfort at T2. Another interaction effect was observed in food-related concerns at T2.
(Lum et al., 2018b)  USA	Randomized control trial  To compare and assess the effects of an easy-to-read advance directive (AD) versus an ACP web site plus the AD (PREPARE + AD) on Behaviour Change Processes and	Primary care patients in the San Francisco Veterans Affairs Health Care System (SFVA).	N=414; n=205 PREPARE + AD group; n=209 in the AD-only group  Female 9%; mean age 71.1 years  Inclusion criteria: >than or equal to 60 years, fluent in English, primary care patients, with two comorbidities, had two or more visits with a primary care	PREPARE is an evidence-based, interactive, online ACP program that uses behaviour change techniques including video stories to prepare patients for medical decision making.  The intervention group reviewed the PREPARE + AD in study offices which takes on average 57 minutes in which they	Measurements were made at baseline, one week, three months, and six months after study enrolment.	The Quality-of-Life subscale which includes 10 items, under the Action domain of the ACP Engagement Survey.	Scores increased significantly over time for the quality-of-life action subscale ( $p \leq t$ 0.005).



	Actions, including discussions and documentation.		<p>clinician in the past year, and had at least two additional clinic, emergency department, or hospital visits in the past year.</p> <p>Exclusion criteria: Patients with evidence of dementia, blindness, cognitive impairment, delirium, psychosis, or active substance abuse on screening.</p>	completed the 82-item ACP engagement survey compared to AD-only group where participants reviewed and evidence-based easy-to-read AD in study offices for five to 20 minutes.			
(Okada et al., 2022)  Japan	<p>Non-randomized controlled trial</p> <p>The purpose of this study was to clarify the relationship between ACP discussions with medical professionals and knowledge and attitudes about ACP and quality of life in older patients</p>	Participants were recruited from patients registered in an online research company that met the criteria.	<p>N=230; n=115 intervention; n=115 control</p> <p>Inclusion criteria: 65 years and older, chronically ill with at least on hospital visit every three months, never received palliative services, being independent in daily living activities, and able to go to the hospital on their own.</p> <p>Exclusion criteria:</p>	<p>The intervention in this study was the introductory part of the ACP discussion covered in Education for Implementing End-of-Life Discussion (E-FIELD).</p> <p>The intervention was lasted approximately 1 hour, conducted in a conference room in a one-on-one setting delivered by nurses who completed a two-day ACP facilitator training.</p>	Questionnaire survey was conducted online by entering responses into a web-based questionnaire which administered at two time points: pre-intervention and 6 months post-intervention.	Comprehensive Quality of Life Outcome (CoQoLo) scale	A statistically significant association was detected between the change in comprehensive QoL and the presence of ACP discussions (P=0.01).

	with stable chronic disease.		The investigator judging that the patient had difficulty with understanding and completing the questionnaire, had serious physical and mental symptoms, and having difficulty understanding Japanese.				
(Overbeek et al., 2019) Netherlands	Cluster randomized controlled trial  To determine the effectiveness of advance care planning in frail older adults	16 residential care homes in the Netherlands  Care home residents and community-dwelling adults receiving home care.	N=201; n= 101 intervention; n= 100 control; female 69 (68%); mean age 87 plus/minus 6.0 (75-102)  Inclusion criteria: Participants were 75 years and older, frail, capable of consenting to participation and living in residential care homes or in the immediate surroundings while receiving home care.	Adjusted Respecting Choices ACP program which involves trained facilitators who assist individuals in exploring the understanding of their illness; reflecting on goals, values, and beliefs; discussing health care preferences; and appointing a surrogate decision maker, was modified for use in this Dutch context.  The average number of facilitated conversation was 125 minutes long. The average number of facilitated conversations per	Intervention participants subsequently engaged in the ACP program with a follow-assessment after 12-months.	Quality of Life as a secondary outcome measure; Generic health-related quality of life was measured using the 12-item Short-Form Health Survey (SF-12)	No significant difference in SF-12 change scores in the Physical Component Score (p = 0.98) and Mental Health Component Score (p = 0.71).

				participant were 1.6 based on the information provided by the participants. The average time between baseline assessment and completion of the study was 47 days.			
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#### 4. Discussion

This review is so far, the first literature review to examine the association between ACP on the QoL in elderly patients in primary health care and community care including home-based and nursing home patients. The studies included in this review are heterogenous in terms of advance care planning approach interventions. There are several literature reviews (Houben et al., 2014; Kelly et al., 2019; Ng et al., 2022; E. J. Park et al., 2021; Weathers, O’Caoimh, et al., 2016; Zwakman et al., 2018) that indicate positive effects of ACP on several different outcomes, but this review focuses only on the ACP effect on QoL in elderly patients.

All but one included study (Okada et al., 2022) had more than one outcome measurement over time with the patients after the ACP intervention. The results are supported by a study which concludes that ACP should be performed over multiple visits rather than a single intervention (Park et al., 2021). Furthermore, these results are supported by an integrative review which emphasizes that ACP should be a part of everyday practice and something that occurs over time, rather than a single event (Combes et al., 2019). A systematic review postulates a similar conclusion that ACP should be incorporated into routine practice for nursing home residents and their family members to allow timely decision-making for end-of-life care preferences (Ng et al., 2022). Which makes long-term care homes as excellent environments for this where developing trusting relationships between frail elderly patients, their families and healthcare professionals can be accomplished (Combes et al., 2019).

Three studies included in my review (Deng et al., 2020; Lum et al., 2018; Okada et al., 2022) showed a statistically significant relationship between ACP and QoL. Two studies (Chan et al., 2021; Overbeek et al., 2018) showed no significant effect between ACP on QoL. The study from Overbeek et al. (2021) described that the participants appreciated ACP and the effects on QoL might have been greater shortly after the intervention and diminished overtime and therefore suggested the importance of doing QoL measurement in relation to ACP discussions.

A paper on relational ethics brought to light the inadequacies concerning end-of-life care and planning for elderly patients in nursing homes during the Covid-19 pandemic (Parks & Howard, 2021), and introduced concepts of relational autonomy and the importance of ACP conversations. However, evidence show that elderly patients are focused on living well now,

maintaining quality of life, rather than on future planning (Combes et al., 2019). Participants commented that the hospital setting was not ideal to introduce ACP. Instead, these discussions were best carried out in a family physicians office or during home visits (Tianshu Angela et al., 2020). For example, a study on ACP programs in the community setting demonstrated increased QoL in patients with dementia diagnosis (Hilgeman et al., 2014). A more recent study showed that elderly preferred place of death are nursing homes over hospital for those who have been residents there over two years (Xu et al., 2023). In connection with these findings, and with United Nations (UN) data predicting the increasing population of elderly globally is due to advancements in medical technology and thus the demand for long-term home-based or nursing home care due to functional and cognitive decline (UN, 2020), policymakers should consider allocating more resources to support nursing home facilities to establish and implement a structured ACP program (Ng et al., 2022).

In my review, four studies had one-on-one direct personal discussions with healthcare professionals which were trained to conduct ACP interventions. With three studies using trained nurses (Deng et al., 2020; Okada et al., 2022; Overbeek et al., 2018) and one study (Chan & Yu, 2021) had group discussions with social workers. A recent meta-analysis shows supporting evidence describing the importance of a trained healthcare provider to facilitate and deliver ACP interventions in nursing home settings (Ng et al., 2022) Another study adds that a major misconception is that ACP is the same as end-of-life decision making, and that this type of discussion should only be conducted by physicians (Killackey et al., 2020). In addition, clinical settings focuses much on medical treatments which undermines the importance of discussions that nurses have with patients and their families about life's goals before death (Killackey et al., 2020).

#### **4.1 Limitations**

The systematic review had some limitations. First, only papers written in English and Norwegian were included, possibly omitting important and relevant studies. Second, findings in this review are limited by not including other study designs such as pilot and feasibility studies. Qualitative studies might also offer insights on stakeholder perspectives on ACP. Several important outcome measures need to be included. General applicability of findings

from this study need to consider the cultural differences between study populations and preferences for autonomy and views on quality of life. Lastly, only one researcher did the search, screening and data extraction but discussed the process with the supervising professor.

#### **4.2 Implications for practice and future research**

There is increasing utilization of advance care planning in clinical settings worldwide and has documented positive effects on several outcomes. However, there is a wide variety of identified outcome measures, ACP intervention programs as well as several different instruments to assess the effectiveness of these interventions on identified outcomes. Therefore, there ACP interventions and outcomes need to be standardized. Further studies are necessary to explore the effectiveness ACP interventions on the elderly population in different clinical settings.

#### **Conclusion**

Considering the significant beneficial effects of advance care planning interventions on increasing awareness and documentation of end-of-life preferences, advance care planning is recommended in community care settings including nursing homes. Future studies will be needed to examine the essential components to what constitutes an effective advance care planning intervention. Identification of outcome measures and appropriate instruments to successfully capture and measure these outcomes need to be applicable in culturally diverse groups and consideration of the elderly patients increasing cognitive impairment are crucial.

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## 2. Reflection paper

### 1. Introduction

Quality of life studies often use patient reported outcomes (Haywood et al., 2015; Kyte et al., 2016; Schwartz et al., 2017). A patient-reported outcome (PRO) is defined as any report coming directly from patients, without interpretation by physicians or others, about how they function or feel in relation to a health condition and its therapy (Patrick et al., 2007). PRO is a broad term that includes direct subjective assessment by the patient of elements of their health including for example health-related quality of life (Margaret L. Rothman et al., 2007).

Structured self-reports are a powerful data collection method that can be readily analysed statistically (Polit & Beck, 2021). Although, erroneous interpretations and misapplication of PROs could however lead to ill-informed decisions or adopting policies that could be detrimental to patients (Kwon et al., 2019). In my review, all five studies included elderly or frail elderly participants using self-reports from the participants themselves and not from relatives or other health care professionals (Chan & Yu, 2021; Deng et al., 2020; Lum et al., 2018a; Okada et al., 2022; Overbeek et al., 2018).

The whole point of PROs is to measure patients' experiences, and the measurement properties of an instrument have little meaning if it is not measuring something valuable to the patients (Patrick et al., 2007). Thus, making it imperative to incorporate the patient's own perspective on the illness experience and the effects of therapy in implementing regulations expected to affect quality-of-life (M. L. Rothman et al., 2007). Quality of life (QoL) and health-related quality of life (HRQoL) are common constructs measured by PROs (Meadows, 2011). QoL is described as a general concept that implies an evaluation of the impact of all aspects of life on general well-being (Patrick et al., 2009). QoL is based on the individual's subjective evaluation of the psychological, physical and social aspects of their life which is changing over time as a result of treatment, while HRQoL refers to the degree to which treatment and the disease to impact in those aspects of their life which they consider important (Speight et al., 2009).

Self-report methods using PROs have some weaknesses, and the most serious issue concerns their validity and accuracy (Polit et al., 2021). Therefore, the aim of this thesis is to identify the challenges in using PROs in measuring QoL in elderly patients.

## **2. Involvement of elderly participants in identifying outcome measures in PROs**

PROs should include concerns that reflect patient views on what they consider as important to them in different health states (Bentur et al., 2010). Patients are more likely to participate in research if they perceive the research to be relevant to them, and selecting relevant outcomes is a path to patient centred research (Polit & Beck, 2021). A Delphi study involving older adults identified functional limitations, emotional wellbeing, social functioning, and quality-of-life as crucial health domains and as their preferred health outcome (Pel-Littel et al., 2019). Unfortunately, results from a scoping review show that in the process of developing PROs, regardless of patient groups, only 10.9% included patient involvement in identifying which outcome to measure (Wiering et al., 2017). A study shows that involving frail older patients in identifying outcome measures are feasible in early parts of the study while they still have the mental capacity, but involvement of relatives are paramount if substantial physical and cognitive impairment in the elderly (Hansen et al., 2021). A recent study shows that there is no validated PRO that is specific for frail elderly patients requiring acute care (Phelps et al., 2022). Fortunately, there is an ongoing study that aims to develop a novel instrument specifically measure autonomy aspects for frail elderly patients receiving acute healthcare (van Oppen et al., 2023). In my review however, participants involved were either receiving community health care including nursing homes (Chan & Yu, 2021; Deng et al., 2020; Overbeek et al., 2018) or primary health care (Lum et al., 2018a; Okada et al., 2022). A systematic review shows that older care-home residents can be successfully involved as collaborators in research (Backhouse et al., 2016). Another systematic review focusing on older people's perspectives which included participants in primary healthcare and home healthcare included feeling safe, feeling like a meaningful human being and maintaining control and independence as fundamental wishes regarding ambulatory healthcare (Herrler et al., 2021). A recent study stresses that ethical considerations are essential in engaging frail and seriously ill patients in research (Ludwig et al., 2021). All but one of the studies in my review (Chan & Yu, 2021) did not mention approval from an ethics committee.

In addition, ACP is identified as a possible potential solution to patient-centred care and preserving patients' autonomy and has been implemented in several countries but unfortunately uptake of ACP remains low (Ding et al., 2022). All five studies in my review increased awareness of ACP but despite this, two studies did not have significant effects on the quality-of measure. One of which Overbeek et al. (2021) can be attributed to the Dutch

healthcare context which often opt less aggressive care or hospitalization of nursing home residents, which may mean that there is less to be gained from ACP. The other study Chan et al. (2021) showed the effects of ACP for enhancing QoL as inconclusive but despite this, findings refuted the concern that ACP discussions may distress elderly patients. Therefore, it is important to consider what is important and relevant for the elderly patients and include these in outcome measures.

### **3. Inclusion of culturally valid quality-of-life measures in PROs**

Quality-of-life measures in the elderly should be adequately assessed, and if necessary, adapted for the culture and population (Pettit et al., 2001). The basic composition of QoL is the same for all people but substantial variations in the extent to which components are individually valued because of cultural and socio-economic differences (Cummins et al., 2004). An original instrument that has been adapted and translated for use for a different cultural group is a measure of cross-cultural validity (Polit & Beck, 2021). For example, a systematic review on self-reports measuring patient dignity showed that almost all studies included instruments that were not validated for use in culturally different populations (Lam et al., 2022). According to one study included in my review Overbeek et al. (2018), future ACP research should investigate the effects of ACP while also considering the effect of culture, study population, and study setting. Another included study in this review Deng et al. (2020), presented hypothetical scenarios as a strategy to make participants aware of the severity and risks of possible outcomes, based on the fact that discussing death is traditionally taboo on the Chinese culture which affirms the study to be culturally sensitive in its methodology. A third study from Lum et al. (2018) used a developed and comprehensive ACP survey that was literacy and culturally validated.

The studies in my review used different quality of life instruments namely the Modified Quality of End-of-Life Questionnaire (mQOLC-E) (Chan & Yu, 2021; Deng et al., 2020), Comprehensive Quality of Life Outcome (CoQoLo) (Okada et al., 2022), Short-Form 12 (SF-12) (Overbeek et al., 2018) and the Quality-of -Life Subscale (Lum et al., 2018a). The respective studies mentioned that the instruments used demonstrated good validity and reliability on the population of older adults within the included cultural population as well as valid for frail chronically ill and multimorbid elderly (Chan & Yu, 2021; Deng et al., 2020; Okada et al., 2022; Overbeek et al., 2018). A study concluded on the psychometric properties

of SF-12 instrument, which was used in one of my included studies (Overbeek et al., 2018), showed to be a useful among the community-dwelling elderly population and the resulting health domains correlates highly with other functional, physical and mental measures (Bentur et al., 2010). Polit & Beck (2021) explains that the crucial idea is that there exists an identifiable set of core, essential, and fundamental building blocks of life quality that are common to us all, irrespective of culture, and these can be captured in generic QoL instruments. This is supported by Cummins et al. (2004) describing generic instruments representing the 'gold standard' for QoL measurement because their values are directly comparable between groups and individuals.

A high score on a QOL measure indicates a positive state of mind, which reflects the adaptive employment of control and ability to make decisions, which in turn is highly dependent on culture (Grossmann et al., 2014). Cultural values and beliefs influence how one perceives illness which in turn influence decision making and healthcare utilization in end of life (Johnson et al., 2008). Results from one study in my review Overbeek et al. (2021) described that the decision to withhold or withdraw potentially life-prolonging treatment are more common in Netherlands and that Dutch has a history of avoiding overtreatment. The study findings from another of the included studies in my review (Chan et al., 2021), conclude that even though the participants may be more motivated to communicate with family members about advance directives (ADs), communication between older adults and family members is often challenging in the Hong Kong Chinese context. Chan et al. (2021) recommends future ACP intervention programmes to include family members as they play a key role as healthcare proxies of older adults, while Overbeek et al. (2021) recommends future research that investigate considering the effects of culture, study population, and study setting. A study adds that control is also dependent on the ability to exercise personal autonomy (Cummins, 2005). One study included in my review (Deng et al., 2020), concludes that ACP intervention promoted the participants' autonomy and broke through the traditional Chinese custom of avoiding discussions about death.

#### **4. Consideration of cognitive and mental decline involving elderly patients in PROs**

There are recent studies using PRO instruments that support the hypothesis that cognitive impairments and depressive states negatively impacts the HRQoL in community-dwelling older adults (Brandão et al., 2020; Liang et al., 2022; Tseng et al., 2020). Disease states such



as dementia and events such as stroke alters a person's physical and mental status thus alternates a person's metacognitive abilities, and this can be a potential threat to the validity of QoL assessment (Blanc et al., 2013). All the five studies in my review (Chan & Yu, 2021; Deng et al., 2020; Lum et al., 2018a; Okada et al., 2022; Overbeek et al., 2018) included participants that were deemed mentally competent and were capable of consenting to the research study. One of the included studies in my review Overbeek et al. (2021) excluded potential patients with dementia and cognitive disabilities using the Mini-Mental State Examination. Another included study (Deng et al., 2020), used the screening version in Chinese of the Montreal Cognitive Assessment (MoCA) to screen for cognitive competence. Three studies of the included studies (Chan & Yu, 2021; Lum et al., 2018a; Okada et al., 2022) did not specify which instrument to test mental and cognitive competence but mentioned in the participant selection that those who were mentally unfit were excluded from the study. Overbeek et al. (2018) used the Mini-Cog assessment at 12-months assessment post-intervention to eliminate participants who were no longer mentally competent to where a relative was then approached for a telephone interview. Two studies included in my review (Chan & Yu, 2021; Okada et al., 2022) piloted and revised their questionnaire after feedback from older adults.

## **5. Conclusion**

Using patient-reported outcomes have been known to be crucial in data collection in QoL studies and have the potential to fundamentally shape practice. Although to ensure the validity in the interpretation and synthesis of results, certain measures must be taken into consideration. This reflection paper focused on three identified challenges in using PROs in measuring QoL in elderly patients. Namely, involvement of elderly patients in identifying and developing PRO measures, use of culturally sensitive instruments and considering multimorbidity and the cognitive decline especially in the frail elderly population especially in studies that vary over time and have multiple assessments. By reflecting on how PROs are developed and constructed and by taking into account the vulnerable and progressing cognitive and mental disabilities of using chronically and frail elderly participants with different cultural backgrounds, researchers should use caution and vigilance in its application in clinical practice.

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## Supplementary materials

**Supplementary Material Table 1. PICO**

Parameters	Inclusion Criteria	Exclusion Criteria
Population	Elderly	
Intervention	Advance care planning	Advance care planning as part of other intervention approaches such as palliative care
Comparators	Usual care	
Outcomes	Quality of life Health-related quality of life	
Study design	Quantitative primary studies: Randomized controlled trials Quasi-experimental studies Non-randomized controlled trials Intervention studies on ACP in primary health care or community-based care settings	Qualitative studies Mixed-method studies Systematic reviews and meta-analyses Editorials Grey literature Unpublished literature Intervention studies on ACP outside primary health care or community-based care settings such as hospital and emergency care

**Supplementary material Table 2. Electronic database search on CINAHL (17.02.2023)**

EBSCOhost-CINAHL	Text search terms	Results
S1	TI (advance care planning or acp) OR AB (advance care planning or acp)	5,247
S2	(MH "Advance Care Planning")	4,844
S3	S1 OR S2	7,560
S4	(MH "Quality of Life +)	147,406
S5	TI (quality of life or qol or health-related quality of life or hrqol) OR AB (quality of life or qol or health-related quality of life or hrqol)	161,656
S6	S4 OR S5	217,375
S7	(MH "Aged+")	938,329
S8	TI (aged or elderly or older people or frail elderly or older adult* or geriatric or senior*) OR AB (aged or elderly or older people or frail elderly or older adult* or geriatric or senior*)	438,106



S9	S7 OR S8	1,164,499
S10	S3 AND S6 AND S9	416
S11	Limiters set on English and Norwegian languages only	330

### Supplementary material Table 3. Search strategy

Search Details	CINAHL	Medline	PsychInfo	Total Citations
Search #1: “advance care planning.mp” OR “advance care planning+” or “ACP”	7560	22 315	1829	31 704
Search #2: “quality of life” OR “qol” OR “health-related quality of life” OR “hrqol”	217 375	459 224	104 887	781 486
Search #3. “aged” OR “aged+” OR “elderly” OR “older people” OR “frail elderly” OR “older adult” OR “geriatric” OR “senior”	1 164 449	6 038 179	763 654	7 966 282
#1 AND #2 AND #3	416	818	135	1369
Number of articles reviewed from combined searches	330	497	85	912

### Supplementary material Table 4a. JBI Critical appraisal for RCTs

	Lum et al., 2018	Overbeek et al., 2018
1. Was true randomization used for assignment of participants to treatment groups?	Y	Y
2. Was allocation to treatment groups concealed?	Y	Y

3. Were treatment groups similar at baseline?	Y	Y
4. Were participants blind to treatment assignment?	N	Y
5. Were those delivering treatment blind to treatment assignment?	N	N
6. Were outcome assessors blind to treatment assignment?	Y	N
7. Were treatment groups treated identically other than the intervention of interest?	Y	Y
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Y	Y
9. Were participants analysed in the groups to which they were randomized?	Y	Y
10. Were outcomes measured in the same way for treatment groups?	Y	Y
11. Were outcomes measured in a reliable way?	Y	Y
12. Was appropriate statistical analysis used?	Y	Y
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	Y	Y
Bias risk (%)	84,62	84,62

**Supplementary material Table 4b. JBI Critical appraisal for quasi-experimental studies**

	Chan et al., 2021	Deng et al., 2020
1. Is it clear what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Y	Y
2. Were the participants included in any comparisons similar?	Y	Y
3. Were participants included in any comparisons receiving similar treatment (care, other than the exposure or intervention of interest)?	Y	Y

4. Was there a control group?	Y	Y
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	N	Y
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Y	Y
7. Were outcomes measured in a reliable way?	Y	Y
8. Were outcomes measured in a reliable way?	Y	Y
9. Was appropriate statistical analysis used?	Y	Y
Risk of bias (%)	88,9	100

**Supplementary material Table 4c. Risk of bias assessment with Robins-I**

	Okada et al., 2022
Risk of bias due to confounding	Moderate
Bias in selection of participants into the study	Moderate
Bias in classification of interventions	Low
Bias due to deviations from intended interventions	Low
Bias due to missing data	Low
Bias in measurement of outcomes	Low
Bias in selection of the reported results	Low
Overall risk of bias	Low

## Attachment File 1: PRISMA 2020 checklist

Section and Topic	Item #	Checklist item	Location where item is reported
<b>TITLE</b>			
Title	1	Identify the report as a systematic review.	Front page
<b>ABSTRACT</b>			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Fifth page
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	1-2
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	3
<b>METHODS</b>			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	3
Information sources	6	Specify all databases, registers, websites, organizations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	3
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	3
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	3-4
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	4
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	4
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	N/A
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	4-5
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	N/A
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	N/A
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A

Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
<b>RESULTS</b>			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	5
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	5
Study characteristics	17	Cite each included study and present its characteristics.	6-7
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	8-9
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
<b>DISCUSSION</b>			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	14-15
	23b	Discuss any limitations of the evidence included in the review.	15
	23c	Discuss any limitations of the review processes used.	16
	23d	Discuss implications of the results for practice, policy, and future research.	16
<b>OTHER INFORMATION</b>			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A

Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

## Attachment File 2: International Journal of Nursing Studies guidelines for authors



# INTERNATIONAL JOURNAL OF NURSING STUDIES

## AUTHOR INFORMATION PACK

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### DESCRIPTION

The *International Journal of Nursing Studies* (IJNS) provides a forum for original research and scholarship about **health care** delivery, organisation, management, workforce, policy and research methods relevant to **nursing, midwifery** and other health related professions. The *IJNS* aims to support evidence informed policy and practice by publishing research, systematic and other scholarly reviews, critical discussion, and commentary of the highest standard.

The journal particularly welcomes studies that aim to evaluate and understand complex health care interventions and health policies and which employ the most rigorous designs and methods appropriate for the research question of interest. The journal also seeks to advance the quality of research by publishing methodological papers introducing or elaborating on analytic techniques, measures, and research methods.

The journal has been publishing original peer-reviewed articles of interest to the international health care community since 1963, making it one of the longest standing repositories of scholarship in this field. The IJNS offers authors the benefits of:

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The IJNS endorses the Equator Network (<http://www.equator-network.org/>) an international initiative that seeks to improve reliability and value of research literature in health care by promoting transparent and accurate reporting of studies. We ask our authors to make use of appropriate

reporting guidelines to ensure excellence in scientific reporting. Guidelines for authors can be accessed at <https://www.editorialmanager.com/NS/default.aspx>.

Authors are also welcome to submit to *IJNS*'s open access companion title, [International Journal of Nursing Studies Advances](#), which welcomes excellent original research, reviews and discussion relevant to nursing, midwifery and other health related professions around the globe.

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Nurses, midwives, educators, administrators and researchers in all areas of nursing and caring sciences.

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### INTRODUCTION

The *International Journal of Nursing Studies* (IJNS) provides a forum for original research and scholarship about **health care** delivery, organisation, management, workforce, policy and research methods relevant to **nursing, midwifery** and other health related professions. The IJNS aims to support evidence informed policy and practice by publishing research, systematic and other scholarly reviews, critical discussion, and commentary of the highest standard. Papers should address issues of international interest and concern and present the study in the context of the existing international research base on the topic. Studies that focus on a single country should identify how the material presented might be relevant to a wider audience and how it contributes to the international knowledge base.

#### *1.1 Types of papers and word limits*

The IJNS publishes original research, reviews, and discussion papers. Full papers can be a maximum of 7000 words in length (excluding references and 1 in tables or figures), although shorter papers are preferred. In addition we publish shorter editorials and letters, which comment on current or recent journal content.

#### **1.1.1 Research Papers — 2,000–7,000 words**

IJNS publishes original research that matches the aims and scope of the journal. Research papers should adhere to recognised standards for reporting (see guidance below and the [Author Checklist](#)). Instrument development or validation papers are only considered if accompanied by a copy of the full instrument, included as a supplementary file at submission stage so it can be published as an appendix online if accepted.

#### **1.1.2 Reviews and Discussion Papers — 2,000–7,000 words**

We publish systematic reviews (addressing focused research questions) and broader literature reviews (such as scoping reviews). We also publish discussion papers, which are scholarly articles of a debating or discursive nature. In all cases, there must be engagement with and critical analysis of a substantive body of research or other scholarship. Systematic reviews should adhere to recognised standards for reporting (see guidance below and the [Author Checklist](#)). We welcome papers that introduce or elaborate on novel or under used methods, or approaches to analysis with substantial significance for the discipline. Such papers can be submitted as a review or discussion paper as appropriate and should represent significant advances and / or be authoritative accounts of the 'state of the art'.

#### **1.1.3 Letters to the editor — up to 1000 words**

Designed to stimulate academic debate and discussion, the Editor invites readers to submit letters that refer to and comment on recent content in the journal, introduce new comment and discussion of clear and direct relevance to the journal's aim and scope or briefly report data or research findings that may not warrant a full paper. Letters are restricted to a maximum of 10 references, from up to 5 authors

#### **1.1.4 Editorials — up to 1000 words**

Authors who have ideas for editorials which address issues of substantive concern to the discipline, particularly those of a controversial nature or linked directly to current/forthcoming content in the journal, should contact the Editor in Chief ([ijns@kcl.ac.uk](mailto:ijns@kcl.ac.uk)).

#### *1.2 General guidance and preferred article types*

Selection of papers for publication is based on their scientific excellence, distinctive contribution to knowledge (including methodological development) and their importance to contemporary nursing, midwifery or related professions. We strongly recommend prospective authors to consult our editorial on common reasons papers are rejected, which outlines avoidable pitfalls as well as the types of articles we prefer <https://doi.org/10.1016/j.ijnurstu.2016.03.017>.

Our criteria for publication is based on significant contribution to science, reducing important uncertainty and / or raising new questions. Provided studies are properly designed and adequately powered, statistically significant results are not a criteria for publication decisions. The journal welcomes replication studies that seek to verify important results where replication is designed to reduce genuine uncertainty or confirm an important new finding. Prospective authors of such studies can submit the background and methods, describing why and how studies were conducted, for a preliminary review prior to submitting a full paper.

We are unlikely to publish studies of new instruments unless the instrument is useful for directly guiding clinical practice (e.g. diagnostic/screening instruments) and there is validation against a robust criterion. Preliminary instrument development studies indicating the need for further development, translations from one language to another and other pilot studies are unlikely to be accepted. Authors are also welcome to submit to *IJNS*'s open access companion title, [International Journal of Nursing Studies Advances](#), which welcomes excellent original research, reviews and discussion relevant to nursing, midwifery and other health related professions around the globe. We do not publish studies undertaken on animals.

### 1.3 Submission system

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A [Microsoft Word template](#) is available to help guide your manuscript preparation.

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The *IJNS* endorses the Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals, issued by the International Committee for Medical Journal Editors (ICMJE), and to the Committee on Publication Ethics (COPE) code of conduct for editors. Our guidelines should be read in conjunction with this broader guidance. The ICMJE requirements can be found at <http://www.icmje.org/> and the COPE's guidelines at <http://publicationethics.org>.

The work described in your article must have been carried out in accordance with The Code of Ethics of the World Medical Association for experiments involving humans (Declaration of Helsinki) and research on health databases (Declaration of Taipei) <https://www.wma.net/what-we-do/medical-ethics/>. Further information on Ethics in Publishing and Ethical guidelines for journal publication can be found at: <https://www.elsevier.com/authors/journal-authors/policies-and-ethics>

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Submission of an article implies that the work described has not been published previously (except in the form of an abstract, a published lecture or academic thesis), that it is not under consideration for publication elsewhere, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright holder. Preprints can be shared anywhere at any time, in line with Elsevier's [sharing policy](#). Sharing your preprints e.g. on a preprint server will not count as prior publication. To aid editorial decisions about distinctiveness and to avoid redundant or duplicate publication, we ask that you provide full references of any publications drawing on the same data in the journal's [Author Checklist](#). If the sources are not readily available, please upload a copy of the manuscript as supplementary material for editors to consider. If other publications are under review or in preparation this should be mentioned in your letter to the Editor. If the sources are not readily available, please upload a copy of the manuscript as supplementary material for editors to consider.

Relevant results from the wider study must be referred to in the paper and the relationship between this and other publications from the same study must be made clear. It is not sufficient to simply cite a prior publication, rather text must clearly state that results are from the same study. Please see <https://doi.org/10.1016/j.ijnurstu.2008.07.003> for more detailed guidance.

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All clinical trials (as defined by the International Committee of Medical Journal Editors) must be registered in a publicly accessible trials registry and registration must have taken place before any participants were recruited. Please cite the registry, registration number, date of registration and, where relevant, date of first recruitment in both the abstract and in the body of the paper. Details of registration will be reviewed to ensure the manuscript is consistent with the registered study and so authors should not redact registration details (see below 'blinded manuscript'). For all other study types, including systematic reviews, we strongly encourage prospective registration.

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# 3 Manuscript Preparation

## 3.1 Documents required for submission (overview).

Information included in the title page can be extracted to populate the submission system reducing the need for you to rekey important information. Follow the detailed guidance in our [MS word template](#) to aid successful extraction.

**Title page:** (with author details) - This should include the title, authors' names and affiliations, and a complete address for the corresponding author including telephone and e-mail address. Twitter handles for one, or all, authors may also be included on the Title Page. The page should also include the abstract and keywords. A [template word file](#) to help guide you is available.

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### 3.2 Title page

The title page should include the following. It will not be seen by reviewers.

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"We have demonstrated in this review that nurse-led intermediate care reduces hospital stay but increases total inpatient stay" (outcome), NOT "We considered in this review the impact of nurse-led intermediate care on acute stay and total inpatient stay" (process)

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Articles should make no assumptions about the beliefs or commitments of any reader, should contain nothing that might imply that one individual is superior to another on the grounds of ethnic background, sex, culture or any other characteristic, and should use inclusive language throughout. We ask authors to consider that the term 'race' is closely associated with ideologies of scientific racism and has no clearly defined scientific meaning. Its use as a simple description / categorisation of people should be avoided.

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### 4.4 Reporting sex- and gender-based analyses

#### Reporting guidance

For research involving or pertaining to humans, animals or eukaryotic cells, investigators should integrate sex and gender-based analyses (SGBA) into their research design according to funder/ sponsor requirements and best practices within a field. Authors should address the sex and/or gender dimensions of their research in their article. In cases where they cannot, they should discuss this as a limitation to their research's generalizability. Importantly, authors should explicitly state what definitions of sex and/or gender they are applying to enhance the precision, rigor and reproducibility of their research and to avoid ambiguity or conflation of terms and the constructs to which they refer (see Definitions section below). Authors can refer to the [Sex and Gender Equity in Research \(SAGER\) guidelines](#) and the [SAGER guidelines checklist](#). These offer systematic approaches to the use and editorial review of sex and gender information in study design, data analysis, outcome reporting and research interpretation - however, please note there is no single, universally agreed-upon set of guidelines for defining sex and gender.

#### Definitions

Sex generally refers to a set of biological attributes that are associated with physical and physiological features (e.g., chromosomal genotype, hormonal levels, internal and external anatomy). A binary sex categorization (male/female) is usually designated at birth ("sex assigned at birth"), most often based solely on the visible external anatomy of a newborn. Gender generally refers to socially constructed roles, behaviors, and identities of women, men and gender-diverse people that occur in a historical and cultural context and may vary across societies and over time. Gender influences how people view themselves and each other, how they behave and interact and how power is distributed in society. Sex and gender are often incorrectly portrayed as binary (female/male or woman/man) and unchanging whereas these constructs actually exist along a spectrum and include additional sex categorizations and gender identities such as people who are intersex/have differences of sex development (DSD) or identify as non-binary. Moreover, the terms "sex" and "gender" can be ambiguous—thus it is important for authors to define the manner in which they are used. In addition to this definition guidance and the SAGER guidelines, the [resources on this page](#) offer further insight around sex and gender in research studies.

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Standard methods of presenting statistical material should be used. Where methods used are not widely recognised explanation and full reference to widely accessible sources must be given.

Wherever possible give both point estimates and 95% confidence intervals for all parameters estimated by the study (e.g. group differences, frequency of characteristics). Exact p-values should be given to no more than three decimal places. Do not interpret non-significant results as evidence that there is no difference / relationship. The term 'statistically significant' (not just 'significant') should be used to refer to the result of tests and the term clinically important should be preferred to the term clinically significant.



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Always identify the statistical package used (including version). Please note that the package SPSS is NOT short for 'Statistical Package for the Social Sciences' or 'Statistical Product and Service Solution' (these names were abandoned in the 1990s!)

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The decision to publish a paper is based on an editorial assessment and peer review. Initially all papers are assessed by members of the editorial team. The aim is to determine if the paper is within scope, is likely to be of interest to the readership, is making a novel contribution and is of a high quality relative to other submissions to the journal. Editorials and Letters may be accepted at this stage but in all other cases the decision is to reject the paper or to send it for peer review. Occasionally a paper will be returned to the author with requests for revisions in order to assist the editors in deciding whether or not send it out for review. Authors can expect a decision from this stage of the review process within 2-3 weeks of submission.

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