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Understanding the Outcomes of Supplementary Support Services in Palliative Care for Older People. A Scoping Review and Mapping Exercise.

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Abstract

Context: Supplementary support services in palliative care for older people are increasingly common, but with no recommended tools to measure outcomes, nor reviews synthesising anticipated outcomes. Common clinically focussed tools may be less appropriate.

Objective: To identify stakeholder perceptions of key outcomes from supplementary palliative care support services, then map these onto outcome measurement tools to assess relevance and item redundancy.

Methods: A scoping review using Arksey and O'Malley's design. EMBASE, CINAHL, MEDLINE and PSYCHinfo searched using terms relating to palliative care, qualitative research and supplementary support interventions. Papers imported into Endnote™, and Covidence™ used by two reviewers to assess against inclusion criteria. Included papers were imported into NVivo™, and thematically coded to identify key concepts underpinning outcomes. Each item within contender outcome measurement tools was assessed against each concept.

Results: 60 included papers focused on advance care planning, guided conversations, and volunteer befriending services. Four concepts were identified: enriching relationships; greater autonomy and perceived control; knowing more; and improved mental health. Mapping concepts to contender tool items revealed issues of relevance and redundancy. Some tools had no redundant items, but mapped only to two of four outcome themes, others mapped to all concepts, but with many redundant questions. Tools such as ICECAP-SCM and McGill Quality of Life had high relevance and low redundancy.

Conclusions: Pertinent outcome concepts for these services and population are not well represented in commonly used outcome measurement tools, and this may have implications in

appropriately measuring outcomes. This review and mapping method may have utility in fields where selecting appropriate outcome tools can be challenging.

Key message:

Four concepts can be expected as outcomes from non-clinical palliative care services: enriching relationships; greater autonomy and perceived control; knowing more; and improved mental health. These concepts are not well represented in typically used outcome measurement tools, so policymakers should pay attention to ensure that outcomes of such services are appropriately measured.

Introduction

Robust ways of measuring the outcomes of novel services for older people are critically important. This helps in understanding whether there is benefit to such services, and to make investment decisions (1). Outcome measurement is acknowledged to be particularly challenging in some fields, including palliative and end-of-life care for older people (2). It is recommended that outcome measures should be brief (to avoid burden), multidimensional (to recognise the multiple needs and holistic nature of palliative care), psychometrically sound and validated for the population under study, and suited to the clinical task (2). There are also challenges associated with assessing outcomes during a time of deteriorating health, such that declining outcome scores can be appropriately interpreted (3).

In palliative and end-of-life care for older people, (hereafter, end-of-life care, used here to mean care in the last 12-18 months of life), supplementary care is increasingly provided outside usual health and social care providers. Public health and compassionate community approaches have inspired services or interventions provided by volunteers, community networks and non-clinical charitable providers(4-6), although few feature in reviews of service models(7). For the purposes of this review, we call these supplementary support services, with a wide definition given that the composition of these services will differ depending on the context. Examples of such supplementary support services include those provided by volunteers or other community members, or charitably provided services where the support staff are not required to have clinical, social or spiritual care qualifications to fulfil their role. Such support is, however, likely to focus on practical, psychosocial and spiritual needs. This may include future care conversations. There are many types of future care planning, some of which are clinically mediated (e.g. do not resuscitate orders), others involve wider ranging, less formal, conversations (8). Some of the expected outcomes of these supplementary support services may differ from clinically provided services. For example, symptom burden is likely

to be at the forefront of clinical care, whereas an impact on issues such as loneliness, belonging or social support perhaps more anticipated from supplementary support services (9-11). It may be that typically recommended palliative care outcome measurement tools are not the most relevant in these situations.

In choosing an outcome tool, an implicit decision is made regarding what constitutes a successful outcome from a given intervention. It is important that the construct to be measured is clearly identified (12, 13). There is no agreed core outcome set for supplementary, community or volunteer provided interventions towards the end of life. Understanding key concepts underpinning likely outcomes is an important first step to then appraising existing tools to understand which may address these areas. We therefore report a scoping review of qualitative research designed to understand stakeholder perspectives on supplementary or volunteer services for older people towards the end of life. We present how the key concepts from this review enable an appraisal of the relevance of existing outcome measurement tools to facilitate appropriate tool choice.

Methods

A scoping review design was chosen as this addresses an exploratory research question, enabling mapping of key concepts using a systematic approach (14-16). They are commonly used where a large and diverse body of literature needs to be broadly understood in an understudied field. It is reported here using the PRISMA ScR checklist extension for scoping studies (17). As recommended, the study followed the Arksey and O'Malley (15) framework stages for the conduct of scoping reviews combined with the Levac, Colquhoun (16) enhancements: identifying the research question, identifying relevant studies, study selection, charting the data, and collating results (14). A formal assessment of methodological quality of included studies is usually not performed (15, 18). Following identification of key concepts,

these were compared to the questions asked in commonly used generic outcome measurement tools.

Review question

What are the key concepts underpinning anticipated outcomes of supplementary or volunteer end-of-life interventions for older people, as perceived by older people, their family carers, or health and social care professionals?

Mapping question

Are the key concepts underpinning outcomes of supplementary or volunteer end-of-life interventions for older people as determined by the scoping review assessed in potentially relevant outcome measurement tools?

The output of the review is a list of key concepts underpinning outcomes of supplementary or volunteer end-of-life interventions that can be used to appraise and choose from contender outcome measurement tools potentially used in research or service evaluation.

Inclusion and exclusion criteria

As the aim is to understand perceptions of actual or anticipated intervention outcomes we focused on identifying qualitative research that described or interpreted perceived outcomes from a range of supplementary or volunteer services or interventions provided towards the end of life for older people. This could include befriending or support interventions, public health or compassionate community initiatives. We also included studies exploring advance care

planning or guided future care conversations, as these were known components of some supplementary support services (8, 19). Quantitative research pre-defines outcomes, and hence was out of scope, although mixed methods studies where the qualitative component could be separately extracted were included. This concept and context guided our inclusion and exclusion criteria (Table 1).

<Insert Table 1 around here>

Search strategy

Key terms from existing robust reviews of palliative care or related interventions were used as the basis to construct search strings for 'palliative care' combined with terms for 'supplementary support interventions' and qualitative research. If possible, filters for older people were used (Supplemental table 1). We focused database searches on the largest and most comprehensive databases likely to include relevant studies (EMBASE, CINAHL, MEDLINE and PSYCHinfo) from inception to March 2018. As scoping reviews are iterative, given the very large number of relevant studies found a decision was made to not expand the search to other databases, grey literature nor hand searching.

Data extraction and analysis

Titles and abstracts were screened by two reviewers (SD and CW) against inclusion criteria using the Covidence™ programme to manage the process of agreement and flag discrepancies. Papers were included if only some of the paper explored supplementary services or interventions with older people, and if these data could be disaggregated. Disagreements were resolved following discussion. Agreed full texts were imported into NVivo™, and attributes assigned on the study characteristics reported in the supplementary table data. The

full text of each article was carefully read by SD or CW to identify data that could reasonably be understood to refer to something that was a consequence of, or benefit from, the intervention received, and these data iteratively coded within NVivo™. Disagreements were resolved through team discussion. NVivo™ was used to manage the process, including inductive qualitative content analysis. These codes were iteratively compared and contrasted to identify areas of similarity, identify key concepts, and create the analytic framework for the review. Data on these key concepts and core attributes of the paper were then extracted.

Mapping key concepts to outcome tools

There are a large number of potential palliative and end-of-life care outcome measurement tools. For example, reviews of outcome measurement in palliative care have identified over 500 potential outcome instruments available (20, 21). We therefore chose contender tools primarily from the most comprehensive publicly available palliative care instrument library (22), but also assessed newer tools, and those commonly used with older people. This was not intended to be comprehensive, but as an exemplar of how others could use the found concepts to appraise other tools. Contender tools were those which were brief (defined as ≤ 30 items for the purpose of this study), multi-dimensional (e.g. not just focused on a single outcome such as depression) and suitable for use across all diagnoses (e.g. not just for those with cancer). Tools that met these criteria were tabulated. For each individual question within the tool a judgement was made on whether the question addressed one of the key concepts identified from the scoping review. This allowed an understanding of what proportion of questions mapped on to at least one key concept, and how many key concepts were addressed within an individual measurement tool.

Results

Sixty papers were included in the scoping review (Figure 1).

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Papers were from 11 countries (with the bulk from the UK (n=15), US (n=12), Australia (n=11) and Canada (n=7)). Interventions or services reported included advance care planning interventions (n=31), volunteer provided services (n=9), and different forms of community provided services (n=8). Details of papers included in the review are in Supplemental table 2.

Four key concepts were identified from the included qualitative papers reviewed:

- **Enriching relationships:** Relationships engendered feelings of being more cared for, respected, loved, and secure.

- **Greater autonomy and perceived control:** People felt more empowered, understood, consulted.

- **Knowing more:** More involved and informed**.** The intervention promoted a greater level of engagement and knowledge in the patient about their condition.

- **Improved mental health:** People felt less anxious or stressed. They could also be more confident, more independent and more assertive.

Whilst presented separately, there is overlap in these concepts, particularly as they relate to both impacts that are more process oriented (e.g. relationships and a sense of autonomy), and those which have more of an outcome orientation (e.g. knowledge and improved mental health).

Enriching relationships

Central to the perceived utility of the services and interventions provided was the less tangible, relational dynamics that created enriching relationships. Whilst this is complex, it can

be encapsulated in the enduring feeling of being cared for and having someone 'there for them'. These go well beyond physical needs to encompass personhood, to have a sense of humanity:

'They cared about my life, my son, not just my body. (23)p117

Together with input from clinical professionals, the interpersonal work of staff and volunteers provided a sense of 'holistic' care, encompassing a greater range of the patient's needs than would be possible for clinical services alone. There was a sense that services that sit out with the norm of clinical services may have an advantage in facilitating such relationships; they can be supportive, non-instrumental with permission to engage in mundane, but important conversations. The chance to engage in 'small talk' of this sort could be especially valuable for patients approaching the end of life if they lacked other opportunities for 'normal' conversations:

I think the thing with a volunteer is, you're actually out of the illness and out of the problem, so therefore patients can come and talk to you knowing you're not actually a nurse and knowing you're not actually a family member and actually just .. . have a laugh .. . you're just like a listening ear (Susan) (24)p.629.

Attentive, skilful, empathic listening was key to these outcomes, providing an opportunity for the patient to share the psychological burdens of their situation. The feeling of being listened to was accentuated by a perception that the worker/volunteer was easily accessible and had time for conversation. In some cases, the feeling of being carefully listened to was an outcome in its own right:

Before erm I was stuck indoors and when friends or family came to visit they're all very well meant and very pleasant etc but in the great majority anybody that came felt it was their duty to sit down and talk at me, talk at me, talk at me, but

I got that from the radio and the television you know [...] and erm [befriending volunteer] is very prepared to listen. (25)p 161

At one extreme, normal everyday talk allowed the patient to be themselves and be free of the guilt associated with the disease. At the other end of the spectrum, interactions could have more profound effects, serving to confirmed one's personal identity or the meaning of one's existence through the telling of significant life events. (26)p.71).

People felt they were part of a continuous, reliable and ongoing relationship. These bonds increased confidence in those providing care:

I felt that because she knew me right more or less from the beginning, that it was very easy to talk to her about it all . . . you build up quite a bond. (27)p.1398

They [volunteers] were described as "friends but not quite friends" and their capacity to engage with deeper issues that family members felt uncomfortable talking about was important. (28)p8

The notion of a quasi-friendship role expresses many of the advantages and outcomes of this sort of intervention because these are processes and outcomes one would associate with a supportive friendship such as listening, small talk, continuity, reliability, and a feeling of being cared for. Positive changes in state of mind could be mediated through the knowledge that someone cared for them, rather than through tasks or roles. Important examples of this included greater self-esteem and self-respect, born of the knowledge that the patient was cared for and listened to as part of an ongoing relationship. The existence of relationships themselves could be described as a form of impact.

Greater autonomy and perceived control

Much of the included literature explored the experiences of, and outcomes from, advance care planning, where there is a focus on enhancing autonomous choice and perceived control. People value the opportunity to establish their wishes, but it was not always the case that they began with a wish to discuss or consider their care preferences. It was often through structured conversations that patients felt more comfortable about discussing topics that would otherwise have been considered taboo or too difficult to consider. The effect of interventions was critical in enabling patients to express key priorities such as "to be free of pain," "not be short of breath," "to be free from anxiety", and to die in a place of their own choice. Where wishes can be asserted, there is hope that these will be met:

> *... wanted to know their preferences and that this would influence not only how they were treated but also the outcomes of that treatment. This was a powerful stimulus to engage in ACP [advance care planning]. (29)p.1025*

Such a sense of autonomous decision making could reduce anxiety and stress as people felt reassured that their wishes for the future would be respected:

> *One participant was worried about his loss of memory and saw the recording of his wishes as protecting his autonomy. (30)p.176*

People felt that an ability to establish their wishes protected dignity, prevented unwanted treatment, or changes in place of care. This gave a sense of control, especially where there were concerns that wishes might otherwise not be met:

> *One of the reasons I want to have everything written out is because I have a very strong willed family member and it is either her way or the highway and she has this way of twisting around things so that it ends up her way. (31)p.120*

Maintaining one's own priorities could be viewed by patients as a way of ensuring that their interpretation of their situation remained primary, and was not overridden, by others such as those influenced by a culture of 'life at all costs'. Knowing that one's wishes will be respected could allow patients to turn their attention to other matters and make them feel respected and listened to.

Impacts relating to growths in patient autonomy and control relied on input from the worker or volunteer that supported patient capacities. In one paper this was explained as an increase in patient 'voice' or agency, requiring a commensurate and proportional diminution in professional power over the situation. In other cases, the role was theorised more simply as advocacy, in which the worker/volunteer acted as a sounding board and conduit for patient wishes.

Knowing more

This is related to issues of autonomy and control, as, for example, to engage in advance care planning it is necessary that people contemplate the reality of their illness and mortality and to know something about the process of death and dying. Knowing more can lead people to greater acceptance of their situation, potentially with benefits of enabling patients to 'process' the reality of death or lose some of their fear. By knowing more patients could become emboldened to choose for themselves, reassured that they were making the right decision. In other cases, it was simply the opportunity for discussion that led people to consider difficult choices rather than avoid them and put them off. In such cases the sharing of information and experiences can increase comfort and ease in relation to discussing death, sometimes through dispelling unfounded fears. Here, participation in a community support group (Circles of Care) facilitated openness:

> *I want others to know my need so they can better understand my needs. Circles of Care members are now more like family members. The more people you know the better your support (32)p.6*

Information was not only a mechanism to bring about other outcomes, also an outcome in itself, insofar as people often wanted to be aware of more information so they could make informed decisions:

> *Most patients wanted more information…. Having this information was seen as vital in maintaining their ability to hope. This was achieved by relieving fears and by helping control the day to day aspects of life. (33)p.2*

Improved mental health

People expressed benefits relating to reduced anxiety, stress and depression from the caring, relational emotional support offered. Many patients could also benefit psychologically from growing peace of mind about their future care. In addition, for some patients being party to the relationship helping to address the distress they suffered as a consequence of loneliness and neglect:

> *There's no comparison. I mean, before I had them I was depressed, lonely and [...]it's the very knowledge that people care. No, no it's changed my life. (25)p.161*

> *Following advance care planning, some patients felt relieved from depression and indecision regarding the burden of dialysis, uncertainties about their illness, and eventual death. Thus, they felt able to "make a choice," "move on," and "live the rest of their life as positively as possible". (34)p.3*

Interwoven, again, is the importance of a sense of being listened to, that someone has a personal friend-like interest in yourself and your wellbeing.

Mapping key concepts on to outcome tools

We mapped the four key concepts identified in the scoping review onto 12 exemplar outcome measurement tools. These are tabulated (Table 2) and an indication given of how many of the questions within these tools were considered to address the four key concepts from the scoping review.

< Insert table 2 around here>

Some tools have multiple redundant items, where there are questions that do not map on to the identified concepts. This may cause unwanted burden in those toward the end of life. An example is the WHO Quality of Life-BREF (WHO-QOL BREF), where only four of 26 questions were considered to address key concepts identified in the scoping review. Some tools have no or few redundant items, but the items within the tool only map onto one or two outcome concepts. An example is the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) where all 13 items were considered relevant, but only mapped on to two of the key concepts. There are also tools that both have redundant questions that do not map onto our key concepts, and where relevant questions do not map on to all concepts. An example is the The OPQoL-Brief where only half of the questions (7/14) appear relevant, and these are only across two concepts.

Tools where over 50% of the items mapped onto at least one of the key concepts were the Functional Assessment of Chronic Illness Therapy - Palliative Care (FACIT PAL), McGill Quality of Life, OPQOL Brief, Palliative Quality of Life Instrument (PQLI), Quality of life at end of life (QUAL-E), WEMWBS and ICECAP-Supportive Care Measure (ICECAP-SCM).

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Tools that mapped onto ≥ 3 concepts were the McGill QOL, Medical Outcomes Study Social Support Survey (MOS SS), Palliative Care Outcome Scale (POS), PQLI, Qual-E, WHOQOL-BREF and ICECAP SCM. The tools that therefore that have high relevancy with low redundancy are The McGill Quality of Life Questionnaire (35, 36) (17 item questionnaire, with 8 mapping on to three concepts), the ICECAP-SCM (37-40) (7 item questionnaire, with 5 items mapping onto all four concepts), the palliative care quality of life instrument (PQLI)(41) with 4 items mapping on to all four concepts), and the Quality of Life at End of Life (QUAL-E) (42) with 14 items mapping on to all four concepts).

Discussion

When older people and other key stakeholders talk about what matters to those receiving supplementary or volunteer services or interventions towards the end of life they talk about four main concepts: enriching relationships, greater autonomy and perceived control, knowing more, and improved mental health. These are not concepts exclusive to supplementary support services, but are clearly benefits from such care. These are not, however, necessarily the concepts assessed as outcomes in commonly used outcome measurement tools with older people and those towards the end of their lives. Example outcome measurement tools, when assessed against these concepts, often have high numbers of redundant items, or do not assess against each of these concepts. Measuring the outcomes of supplementary support services therefore, using most existing tools risks increasing respondent burden with redundant items, or measuring inappropriate concepts.

The tools that were identified as exemplars as potentially having the highest relevancy with low redundancy were the McGill Quality of Life Questionnaire, the ICECAP-SCM, PQLI and QUAL-E. It may be that providers and researchers of supplementary support services may wish to consider using these tools. Other factors however will also come into play before a

choice of tool for a specific purpose should be made. First, who completes the tool? Some tools are designed for the person themselves (patient, service user) to complete (e.g. The McGill Quality of Life Questionnaire), others for an interviewer to administer (e.g. the QUAL-E). Second, the length of time over which the respondent is asked to recall. Whilst the QUAL-E, for example, asks for recall over the last month, the McGill Quality of Life Questionnaire is the past 2 days. Third, tools also vary in the estimated length of time to complete, and their total number of items. It is not advised to only use the elements from a tool that map onto the concepts identified in this review, as this would not then be a valid measure. Other areas of consideration include whether the tool is validated for a particular population of interest, or translated into particular languages. It is critically important that before a tool is used for a particular purpose or population that there are checks made that it has been tested in that population and found to be valid and reliable.

Challenges will remain, however, in using such outcome tools, however relevant they appear, to measure service outcomes where they are less tangible, prone to individual variation, and in a situation where decline is expected. Some of these issues are conceptual, with questions about whether measurement of the concepts identified from the review such as enriching relationships is even possible. In addition, determining differences between concepts such as autonomy and knowing more may be challenging. Others are pragmatic, about understanding impact for a particular person in a situation of decline over time, and where response shift is likely to occur (43, 44). Ways of understanding benefit that do not purely rely on outcome measurement tools are likely to remain important. In addition, benefit from interventions may be particularly felt when people lack other resources, social support or other networks, and tools do not identify these contextual issues.

Strengths and Limitations of the Review

This was a transparent and robust review with a clear audit trail and quality control procedures. However, due to the very large number of papers found across a wide range of journals we did not enlarge the pool of databases searched nor hand-search journals nor the grey literature. Given the large number of included studies and the clear themes across studies, this limitation is unlikely to have impacted on the findings of the review. Given the relatively large proportion of studies of advance care planning this may have influenced the articulation of the 'knowing more' theme, whereas a study testing these as theoretical propositions within a study of a supplementary support service found that future care planning, and hence knowing more, occurred less than anticipated (19). We did not map concepts onto all contender tools, given the large number of available tools, but offer this as an exemplar for readers to appraise other tools they may consider using in this field.

Conclusions

Analysis of qualitative research enabled identification of four main perceived care outcomes from supplementary palliative care support services. It was possible to then identify whether these concepts were included in exemplar existing outcome measurement tools. This enables an informed choice of existing outcome measurement tools for research and practice, understanding better the areas of relevance and redundancy/burden. This method may lead to fewer new tools being developed, given the plethora of existing tools, unless there is explicit need. Caution is, however, required, as the concepts of interest may be best understood qualitatively.

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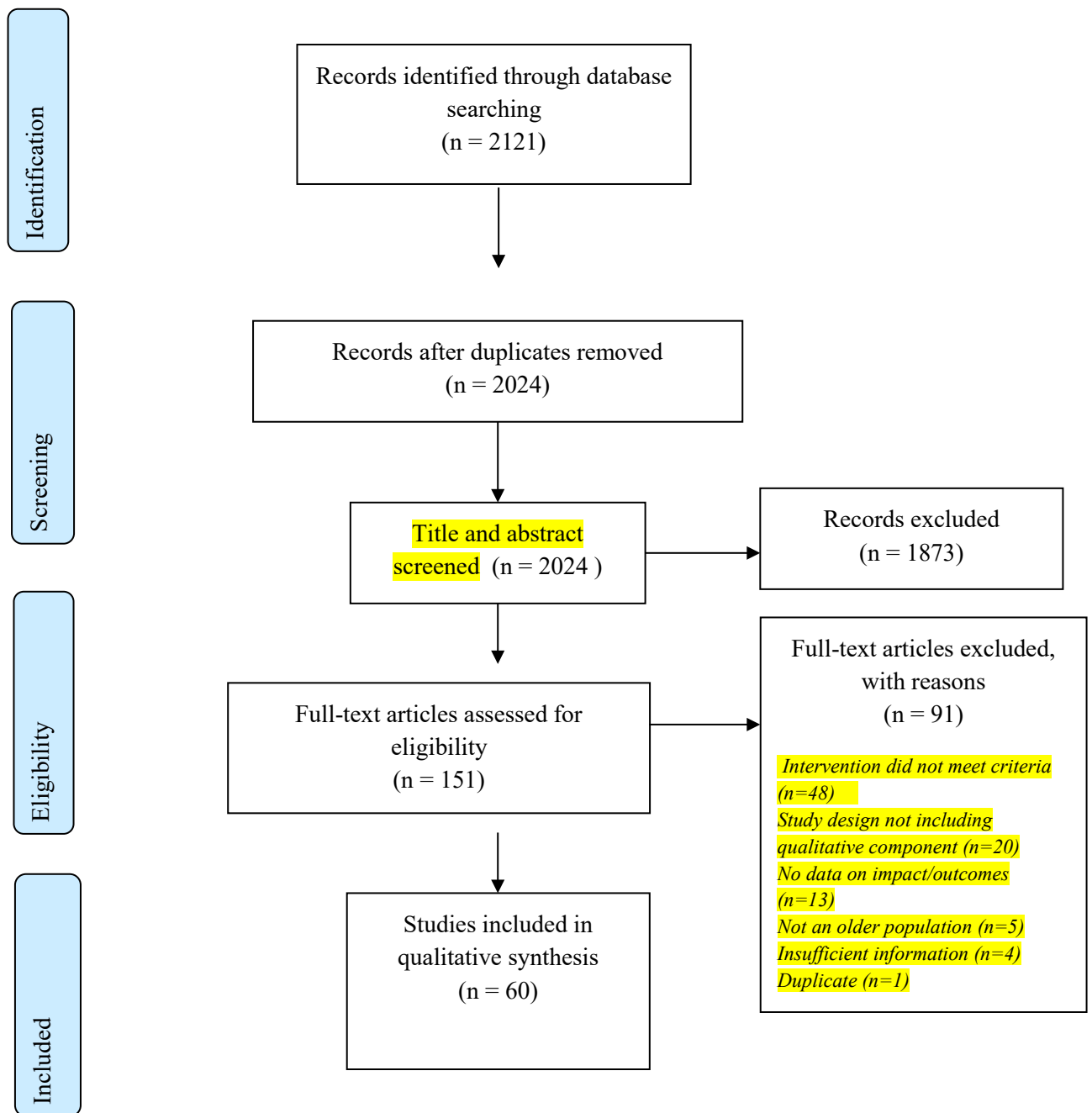
Figure 1. Process of searching for literature

Table 1. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
1. Reports qualitative findings, including those qualitative data that could be extracted from studies also reporting quantitative data.	1. Concerns people with dementia, as advanced dementia towards the end of life may preclude articulation of service impacts.
2. Contains data from older people or describes services for older people (defined as 65+), that could be extracted from studies also including a wider adult population.	2. Published in a language other than English.
3. Contains data on outcomes from the perspective of the older person, their family/carer or staff.	3. Studies of paediatric populations.
4. Concerns outcomes from supplementary support or volunteer services or interventions (e.g. guided conversations, advance care planning, needs assessment, public health or compassionate community initiatives, befriending and support interventions).	
5. The population includes people who could be in their last year of life (e.g. adult cancer patients with incurable disease (defined by tumour staging), or adults with a progressive, life threatening disease (e.g. as defined by New York Heart Association Class) and may include patients classed in the	

literature as 'frail elderly' if receiving a palliative care focused intervention)	

Table 2. Mapping review concepts onto contender outcome measurement tools

Tool name and description	Functional Assessment of Chronic Illness Therapy – Palliative Care 14-item version (FACIT-Pal-14).(45)	EuroQoL Five Dimensions Questionnaire (EQ-5D)(46)	The McGill Quality of Life Questionnaire(36, 47)	Missoula-Vitas Quality of Life Index, 15 Item Version (MVQOLI)(48)	The MOS social support survey(49)	The OPQoL-Brief(50)	Palliative care Outcome Scale (POS)(51)	Palliative Care QOL Instrument (PQLI)(41)	QUAL-E (Quality of Life at End of Life)(52)	The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)(53)	WHO Quality of Life-BREF (WHOQOL-BREF). (54)	The ICECAP Supportive Care Measure (ICECAP-SCM)(40)
Number of key concepts mapped	2	1	3	1	3	2	3	4	4	2	4	4
Questions on improved mental health	6/14	1/5	4/17	0/15	0/20	5/14	3/11	1/7	726	12/13	2/26	1/7
Questions on enriching relationships	3/14	0/5	2/17	2/15	6/20	2/14	1/11	1/7	3/26	1/13	2/26	1/7
Questions on greater autonomy and control	0/14	0/5	2/17	0/15	3/20	0/14	1/11	1/7	2/26	0/13	1/26	2/7
Questions on knowing more	0/14	0/5	0/17	0/15	1/20	0/14	0/11	1/7	2/26	0/13	1/26	0/7
Relevance	9/14 Items relevant in two concepts	1/5 items relevant in one concepts	8/17 Items relevant in three concepts	2/15 Items relevant in one concept	9/20 Items relevant in three concepts	7/14 Items relevant in two concepts	4/11 Items relevant in three concepts	4/7 Items relevant in four concepts	14/26 Items relevant in	13/13 Items relevant in	4/26 Items relevant in four concepts	4/7 items relevant in four concepts

									four concepts	two concepts		