




Care biography: A concept analysis

Matthew Tieu PhD, Research Fellow^{1,2,3}  |
 Regina Allande-Cussó PhD, Associate Professor^{2,4}  |
 Aileen Collier PhD, Associate Professor^{1,2} | Tom Cochrane PhD, Senior Lecturer³ |
 Maria A. Pinero de Plaza PhD, Research Fellow^{1,2}  |
 Michael Lawless PhD, Research Fellow^{1,2} |
 Rebecca Feo PhD, Senior Research Fellow^{1,2} |
 Lua Perimal-Lewis PhD, Senior Research Fellow⁵ |
 Carla Thamm PhD, Senior Research Fellow^{1,2} | Jeroen M. Hendriks PhD, Professor^{1,2} |
 Jane Lee PhD, Research Fellow^{1,2} | Stacey George PhD, Professor^{1,2} |
 Kate Laver PhD, Professor^{1,2} | Alison Kitson PhD, Professor^{1,2}

¹Caring Futures Institute (CFI), Flinders University, Adelaide, South Australia, Australia

²College of Nursing and Health Sciences, Flinders University, Adelaide, South Australia, Australia

³College of Humanities, Arts and Social Sciences, Flinders University, Adelaide, South Australia, Australia

⁴Faculty of Nursing, Physiotherapy and Podiatry, University of Seville, Seville, Spain

⁵College of Science and Engineering, Flinders University, Adelaide, South Australia, Australia

Correspondence

Matthew Tieu, PhD, Research Fellow, College of Nursing and Health Sciences, Flinders University, GPO Box 2100, Adelaide 5001, South Australia, Australia.
 Email: matthew.tieu@flinders.edu.au

Abstract

In this article, we investigate how the concept of Care Biography and related concepts are understood and operationalised and describe how it can be applied to advancing our understanding and practice of holistic and person-centred care. Walker and Avant's eight-step concept analysis method was conducted involving multiple database searches, with potential or actual applications of Care Biography identified based on multiple discussions among all authors. Our findings demonstrate Care Biography to be a novel overarching concept derived from the conjunction of multiple other concepts and applicable across multiple care settings. Concepts related to Care Biography exist but were more narrowly defined and mainly applied in intensive care, aged care, and palliative care settings. They are associated with the themes of *Meaningfulness and Existential Coping*, *Empathy and Understanding*, *Promoting Positive Relationships*, *Social and Cultural Contexts*, and *Self-Care*, which we used to inform and refine our concept analysis of Care Biography. In Conclusion, the concept of Care Biography, can provide a deeper understanding of a person and their care needs, facilitate integrated and personalised care, empower people to be in control of their care throughout their life, and help promote ethical standards of care.

KEYWORDS

biographical approach, care biography, care diary, caring life course theory, person-centred care

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2024 The Author(s). *Nursing Philosophy* published by John Wiley & Sons Ltd.

1 | INTRODUCTION

1.1 | Background

The ethical standard or 'gold standard' of care provision is nowadays captured within various 'person-centred', 'patient-centred', 'relationship-centred', 'integrated', and 'fundamental care' frameworks. While there are significant differences among them, they all have in common an emphasis on personalised and holistic approaches to care (Balint, 1969; Brooker, 2007; Engel, 1977; Feo et al., 2018; Kitwood & Brooker, 2019; McCance et al., 2011; McCormack, 2004; Stewart, 2001). Whether explicitly or implicitly, they are inspired by the humanistic ideals of autonomy, self-actualisation, dignity, and empathy (Rogers, 1957), and recognition of the vital role that appropriate communication and care relationships play in promoting those ideals (Kitwood & Brooker, 2019; Tresolini, 1994). More recently, life course perspectives have contributed to further conceptual and theoretical development of such frameworks, helping us to understand the causal antecedents of a person's care needs, how they shape subsequent health trajectories, and how they inform ongoing holistic care provision throughout the lifespan (Halfon et al., 2014; Kitson et al., 2022; Lawless et al., 2024). Traditionally, our understanding of care focused narrowly on specific health outcomes and goals related to specific conditions and defined timeframes. Such a view fails to consider the nuanced interdependencies and histories that create an ecosystem of care and support, leading to missed opportunities for comprehensive, meaningful and sustainable care strategies. In contrast, life course frameworks compel a greater emphasis on a person's historical and lived experience of illness, a narrative understanding of their care needs, and the complex ecosystem of care and support in which they are embedded. The Caring Life Course Theory (CLCT) developed by Kitson et al. (2022) is one such framework. It adopts a temporally extended and integrated view of a person's healthcare trajectory and is underpinned by a number of theoretical constructs, in particular, 'Care Biography'.

The novel contribution of the theory is the interplay between understanding a person's care needs and provision within the context of their lifespan and personal histories, termed their care biography. (Kitson et al., 2022, p. 1)

Given the increased prevalence of people living with long-term and complex care needs, there is an urgent need to ensure that how we provide care accords with the humanistic ideals captured within those care frameworks. This requires a degree of conceptual clarity and agility in how we understand a person's care needs and how those needs relate to the historical, social, cultural, environmental, and technological contexts in which a person is embedded. Emerging digital technologies that capture and draw from vast amounts of personal information across the lifespan have great potential to help us achieve the ethical ideals of care but can also be misdirected and

misapplied (Tieu & Kitson, 2023; Tieu, 2021). Therefore, integrated, holistic, and personalised approaches to care need to be conceptualised and understood in a way that informs the appropriate development and application of such technologies. Further clarification and development of the concept of Care Biography, alongside related concepts, can provide us with the conceptual tools necessary to ensure that the ethical ideals of care are understood and upheld as we enter an era of rapid and unprecedented technological progress. We hope that this will stimulate further thought and scholarship on some of the deeper philosophical questions related to the assumptions, ideas and understandings of care and its contribution to 'the good life'.

2 | METHODS

2.1 | Aim

The aim of this article is to clarify and develop the concept of Care Biography to enrich our understanding of care, inform new and innovative approaches to record keeping and care provision, and contribute to ongoing development and refinement of care frameworks that capture the humanistic dimensions of care across the life course.

2.2 | Design

We apply Walker and Avant's (2019) eight-step method, which is an iterative process in which revisions to each step are made in light of findings arising from other steps. It enables examination of the characteristics, relationships, and function of an idea or phenomenon, and facilitates proposal of formal definitions. Essentially, we selected Care Biography as our concept of interest and undertook a structured literature search to identify relevant and related concepts. We explored and analysed the literature, then developed a detailed list of defining attributes of Care Biography and described potential model cases of applications of Care Biography.

Step 1: Select a concept: Care Biography is a key construct of the CLCT, which applies a life course perspective toward understanding a person's care needs.

Step 2: Determine aims and purpose of analysis: Our aim was to develop and refine the concept of Care Biography. We did this by searching and reviewing the relevant literature according to Walker and Avant's (2019) eight-step method, as well as engaging with colleagues with expertise across various disciplines, including cardiovascular nursing (JH), emergency department nursing (RAC), cancer nursing (CT), occupational therapy (SG and KL), palliative care (AC), aged care and digital technology (LPL, JL and ML), nursing theory (AK, RF and MAPP) and ethics and philosophy (TC and MT) to provide insights into how the concept could or was being applied in different contexts and settings.

Step 3: Identify uses of the concept: Initial database searches revealed very limited use of the concept of Care Biography. Hence,

we developed a typography of related concepts and terms based on our existing familiarity with the literature and multiple discussions among co-authors. This also enabled us to identify potential borderline, contrary, and illegitimate cases as required for Step 6. We selected the most relevant terms as database search terms and performed a deductive/inductive thematic analysis of the literature.

Step 4: Determine the defining attributes: Based on the initial definition and an analysis of Care Biography from the CLCT, and analysis of related concepts in the literature, we describe the cluster of attributes associated with the concept of Care Biography.

Step 5: Identify model cases: Following on from Step 4 above, we identified model cases of Care Biography in a range of care contexts and settings through discussions among all authors.

Step 6: Identify and examine borderline, related, contrary, invented and illegitimate cases: Results of the literature review and analysis enabled us to identify borderline, related, and illegitimate cases. Additional cases are also considered and briefly discussed.

Step 7: Identify antecedents and consequences: We describe the kinds of events and understandings necessary for development of Care Biographies (antecedents) and their application in care practice (consequences).

Step 8: Define empirical referents: Drawing from the attributes of care biography in Step 4, we describe the kinds of phenomena that may constitute an occurrence of Care Biography and its application.

2.3 | Search methods

As part of Step 3 of the concept analysis, we performed database searches (CINAHL, Scopus and PubMed) using keywords based on a selection of the most relevant terms identified from our initial typography of concepts related to Care Biography. Full-text searches from all available date ranges (up until 23 August 2023) for the following terms were performed: 'care biograph*' OR 'biograph* of care' OR 'biograph* approach*' AND 'care' OR 'care diar*'. Peer-reviewed journal articles and book chapters of any kind (i.e., empirical research, study protocols, reviews, discussion papers, commentaries and editorials), written in English were included. Non-peer-reviewed articles and books, grey literature, dissertations/theses, conference papers, book reviews and any non-English articles were excluded. Only articles that pertained to health care of humans as recipients of care were included. Articles that did not pertain to health care (e.g., social services) of humans as recipients of care (e.g., articles that focused on non-human animals or solely on carers and family members of care recipients) were excluded.

2.4 | Search outcomes

The database searches returned a total of 322 articles for initial screening (Table 1). The web-based platform Covidence™ was used for screening and data extraction. Duplicates were initially removed ($n = 130$) and then title and abstract screening ($n = 192$) followed by

TABLE 1 Search results.

Search terms	CINAHL (EBSCO)	SCOPUS	PubMed
'care biograph*'	8	9	0
'biograph* of care'	1	7	0
'biograph* approach*' AND 'care'	40	54	28
'care diar*'	46	75	54

full-text screening ($n = 119$) was performed by the lead author (MT) based on the inclusion/exclusion criteria outlined above. A total of 71 articles were returned for data extraction and analysis (PRISMA flow diagram in Figure 1).

2.5 | Data extraction, analysis and synthesis

Two authors completed the data extraction (MT and RAC) using Covidence™. An initial analysis of the CLCT definition of Care Biography was performed to identify key attributes. A hybrid deductive/inductive thematic analysis was performed using those attributes as pre-ordinate themes, combined with themes emerging from data extracted from literature (Fereday & Muir-Cochrane, 2006). This enabled us to compare the CLCT definition of Care Biography with related concepts from the literature. Thematic coding for both deductive and inductive components was performed by the lead author (MT) and two additional co-authors (RAC and ML). The analysis provides the basis for further refinement of the CLCT definition of Care Biography drawing from related concepts.

3 | RESULTS

3.1 | Papers describing the concept of interest

Of the 71 included articles, most were empirical research ($n = 46$) and review articles ($n = 15$). Other papers included study protocols ($n = 3$), discussion papers ($n = 3$) and commentaries or editorials ($n = 4$). Initial database searches identified several articles containing the specific phrases 'care biography' and 'biography of care', or similar variations. However, only a few of those articles met the inclusion criteria ($n = 2$ for 'care biography' and $n = 1$ for 'biography of care'). The phrase 'biographical approach' appeared more frequently ($n = 23$) as well as various iterations of 'care diary' ($n = 47$). Most papers focused on a range of patient conditions and care contexts/settings, including intensive care ($n = 24$), aged or dementia care ($n = 13$), cancer care ($n = 9$) and palliative care ($n = 5$), type 1 diabetes among pregnant women ($n = 3$) and other miscellaneous conditions/settings ($n = 12$). A small number of papers did not focus on any specific patient condition or care context ($n = 5$). This information is summarised in Table 2 below.

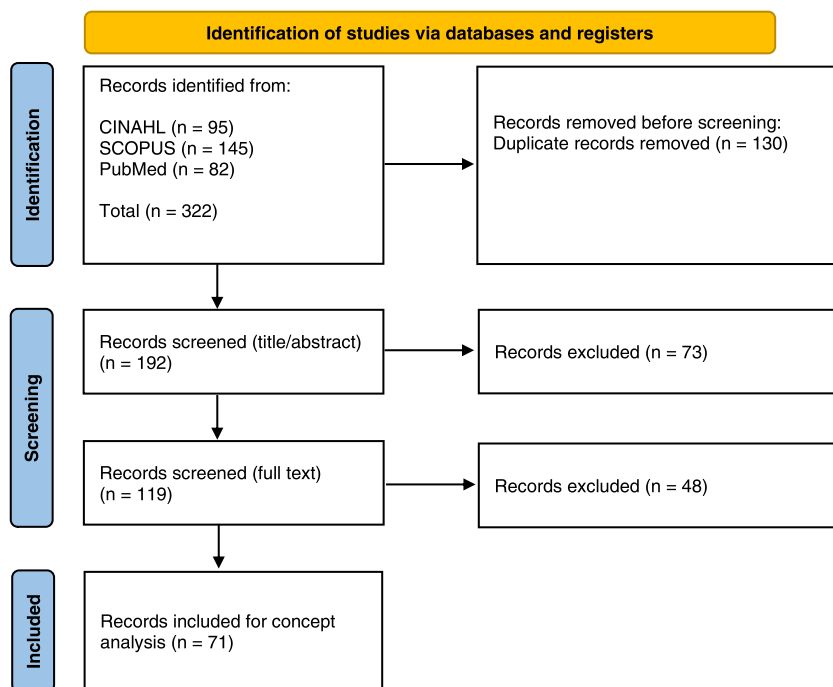


FIGURE 1 PRISMA flow diagram.

TABLE 2 Article information.

Article Information	n
Article types	
• Empirical Research	46
• Reviews	15
• Study Protocols	3
• Discussion Papers	3
• Commentary/Editorial	4
Patient conditions and care contexts	
• Intensive Care	24
• Aged/Dementia Care	13
• Cancer Care	9
• Palliative Care	5
• Type 1 Diabetes and Pregnancy	3
• Non-specific	5
• Other	12
Concept/Construct	
• Care Biography	2
• Biography of care	1
• Biographical Approach	23
• Intensive Care Diary (ICU Diary)	24
• Self-Care Diary	14
• Care Diary	8

One of the two articles that specifically referenced 'care biography' was by Kitson et al. (2022) whose definition of Care Biography is the subject of our concept analysis. The other was by Beasley et al. (2015), a study investigating the lived-experience of volunteers in a 'care biography service' for palliative care patients (Beasley et al., 2015). A similar construct, 'biography of care' was mentioned in a commentary by McMillan (2011) on education and training of care providers (McMillan, 2011). The phrase 'biographical approach', which appeared more frequently was applied mainly in the context of aged or dementia care ($n = 13$), with some application in palliative care ($n = 3$), intensive care ($n = 1$) and various other specific and non-specific care contexts ($n = 6$). It should be noted that reference to 'biographical approach' in several papers pertained specifically to study methodology ($n = 7$) while others were associated with an intervention or review of interventions ($n = 16$). Various iterations of 'care diary' were prevalent, particularly 'intensive care diary' ($n = 24$). The notion of a 'self-care diary' was also prevalent ($n = 14$) with some uses of this term related specifically to the 'self-care diary' (SCD) measurement tool developed by Nail et al. (1991) for cancer patients ($n = 6$).

3.2 | Concepts of interest

3.2.1 | The CLCT definition of Care Biography

Care Biography is a key theoretical construct of the CLCT (Kitson et al., 2022). Our analysis of the CLCT definition revealed that it is comprised of the following three attributes:

1. *A personalised record of a person's self-care capability, capacity, and care preferences*: 'A care biography is equivalent to a personalised health record in that it should record, across the life course, a person's self-care capability and capacity and their preferences in how care is provided for them' (p. 10).
2. *A personalised care plan*: 'It should also help them and their carers plan care following certain negotiated care trajectories. This information would be owned by the individual and used to negotiate care in each care encounter' (p. 10).
3. *A record of a person's care network*: 'Importantly, the care biography should also record each person's care network, identifying their key carers and those for whom they care over their life course' (p. 10).

Essentially, the CLCT definition of Care Biography collects information pertaining to three elements—*preferences, plans* and *people*. The first element generates a person's care and self-care *preferences* while considering relevant abilities and availability of resources. The second element enables a person to be in control of generating a care *plan* at different points in their life, one that both articulates and advocates for their care needs (including fundamental care needs). The third element both captures and informs the *people* who are involved in providing care as part of an extended care network linked to appropriate system and professional support. These elements in conjunction with the attributes of the CLCT definition of Care Biography provide a priori themes and the coding framework for the deductive component of our thematic analysis.

3.2.2 | 'Care biography' and 'biography of care'

The study by Beasley et al. (2015) investigating the lived experience of volunteers involved in a palliative 'care biography' service aims to enable patients to recognise 'what they had accomplished in their lives, and to emphasise the meaningfulness of their lives for themselves, family, and friends' (p. 1417–1418). Given the focus on a patient's life history and accomplishments, the notion of a 'care biography' in this particular instance is one that takes a lifespan perspective of the patient and not of their care needs. The commentary by McMillan (2011), which mentioned 'biography of care' focused on the perspective of care providers and their attitudes towards patients, emphasising how 'stories engage readers more fully than do clinical descriptions' and how those stories 'provide students with language and tools for thinking about and managing, not only their patients, but also themselves and their own emotions' (p. 206). The concept of 'biography of care' in this context was relatively broad and thus embodied the attributes of the CLCT definition of Care Biography in a general sense. However, while their use of the term 'biography of care' identified the relational aspect of care provision, there was no explicit mention of whether any relevant records or documentation were produced in conjunction with carers, patient, and family, or owned by patient (and/or family), nor was there any specific consideration of the broader contexts of care provision.

3.2.3 | 'Biographical approach'

The phrase 'biographical approach' appeared frequently, particularly in aged care, dementia care and palliative care contexts. Many papers emphasised the importance of understanding a patient's lived experience, personal reflections, and personal preferences regarding how they are cared for, taking into consideration the patient's family and social network. Such considerations are often framed in terms of 'person-centred', 'patient-centred' or 'relationship-centred care'. For example, as Ryan (2022) states 'typically, person/relationship-centred care interventions are underpinned by activities and practices that seek to understand the person or patient' and hence 'biographical approaches provide the platform from which care can be organised' (p. 894). Similarly, Surr (2006) describes biographical approaches to dementia care as essentially aimed at preserving a person's selfhood, which is understood as a psychological, social, and biographical construct. The primary focus of these papers was to encourage care staff to connect to the patient as a person. They did not explicitly use the care encounter to build up a picture of the care needs, capabilities, capacities, and preferences of the person receiving care, either at a point in time (synchronic) or across the lifespan (diachronic). Integrated approaches accounting for medical, physical, and psychosocial care needs were a key feature in most of the articles and so too the quality of care relationships. However, consideration of a person's care network was not always a prominent feature, nor was there any explicit mention of whether relevant documentation was produced in conjunction with carer, patient, and family, or owned by patient (and/or family).

3.2.4 | 'ICU diaries'

Papers that mentioned 'ICU diaries' were very consistent in how they conceptualised their purpose and function, how they were produced, and by whom they were owned. The ICU diary is primarily intended to help patients 'fill in the significant gaps they have in their memories and put any delusional memories into context and so aid psychological recovery' (Jones et al., 2010, p. 2). There is much emphasis on facilitating meaning-making, understanding, and coping for the patient and this often involves consideration of their relatives and the role they play in providing ongoing support to the patient. ICU diaries also typically incorporate photographs to visually capture experiences that a patient and/or their family may not clearly recall. In this regard the ICU diary constitutes a highly personalised care narrative involving a patient's broader care network, which is aimed at providing ongoing and integrative care support for patient self-care. While nurses are typically the principal authors of ICU diaries, in some cases family members and friends actively contribute to the diary as co-authors or are encouraged to write separate accounts which are then later added to the diary (Egerod et al., 2011; Ewens et al., 2015). The diaries are typically kept by nurses during a patient's ICU stay and then handed over to the patient and/or their family upon discharge. In this regard, ICU diaries are to some extent owned

by the patient and their family and thus embody all themes from the CLCT definition of Care Biography. ICU dairies also represent the integration of physical, medical, and psychosocial care needs while capturing the crucial role that care relationships and care networks play in addressing those care needs.

3.2.5 | 'Care diary' and 'self-care diary'

Aside from ICU dairies, the notion of a 'care diary' or a 'self-care diary' was associated with a variety of different patient care needs, contexts, and settings. Several papers referred specifically to the 'self-care diary' (SCD), which is a measurement tool for cancer patients (Nail et al., 1991). According to Yahaya et al. (2015) it aims to capture 'all side effects of chemotherapy along with a list of self-care activities' (p. 729). Aside from the SCD, the purpose and function of self-care dairies was primarily condition and context specific, containing information limited to a particular range of medical conditions and self-care practices. Such dairies were often described as providing a resource for patients to inform them of their condition and help them undertake self-care independently or in conjunction with care providers. For example, in a study by Sabzghabae et al. (2012) an asthma care diary was used 'to educate the patient about their asthma and its management' (p. 67), while in a study by Miller et al. (2007) it was stated that an oral self-care diary for chemotherapy patients 'would encourage patient involvement in self-care and promote discussion between patients and their health professionals' (p. 84). In this regard, there is some synergy with CLCT definition of Care Biography in that it facilitates and captures a person's self-care capability and capacity as part of a personalised care record. However, while some of the information contained in such dairies was personalised, there was little to no scope for information regarding personal reflections and lived experience. Additionally, only one article by Sharp et al. (2004) explicitly mentioned any role of family in care dairies, where they state that part of the purpose of dairies was 'to improve information between patients, family members, and clinicians in different settings' (p. 120). Hence, based on the literature identified, the notion of a 'care diary' or 'self-care diary' bears little relation to an ICU diary or the CLCT definition of Care Biography.

3.2.6 | Relation to CLCT definition and themes

Our primary finding was that existing literature describing any aspect of Care Biography is sparse. There was no body of knowledge or understanding of how the concept could enhance person-centred care. The concepts of 'care biography' referred to by Beasley et al. (2015) and 'biography of care' referred to by McMillan (2011) captured the importance of the experiential, existential and relational aspects of care provision and converge on the idea of ensuring health care professionals take more account of the personhood of patients by considering relevant biographical details (Beasley et al., 2015;

McMillan, 2011). This is more explicitly articulated in literature referring to the notion of a 'biographical approach' to care (Ryan, 2022; Surr, 2006). While these considerations are embedded in the CLCT definition of Care Biography, our analysis indicates that they did not necessarily entail a connection between understanding a person's own view of how they care for themselves (self-care), or how they have experienced care from others in the past. This means that the concept of Care Biography, as articulated in the original CLCT definition, is significantly more detailed and multidimensional than these related concepts.

Promising codesign and co-ownership approaches were described in the literature referring to ICU dairies, which reflect the importance of the care context, the relationship between the patient and their carers, and the importance of recording what actually happened to them so they can begin to draw meaning and make sense of their situation (Egerod et al., 2011; Ewens et al., 2015; Jones et al., 2010). However, while eliciting self-care capability and capacity were features of ICU dairies (and also 'self-care dairies' and the SCD), there was a sense that it was more of a medical plan for the benefit of professional care providers and not so much a self-care and self-advocacy tool for patients. The lack of a self-care and self-advocacy focus was also evident in the literature describing care preferences associated 'biographical approaches', which tended to focus on enabling care providers to acknowledge and appreciate the life of their patient rather than enabling them to address their patient's care needs more directly. The lack of a patient focus and direct approach to generating and managing personalised care plans (as opposed to medical plans) reflects a lack of understanding of the difference between point-in-time (i.e., synchronic) care negotiations, and across-time (i.e., diachronic) ebbing and flowing of care experiences, needs and preferences. ICU dairies (and perhaps other 'self-care dairies') could be used to complement 'biographical approaches' to care and serve as a tool to support construction and application of Care Biography (in both ICU and other care settings). However, it is essential to ensure that context, ownership, codesign, and purpose are clear to both patients and healthcare professionals.

3.3 | Key themes from the literature

3.3.1 | Meaningfulness and existential coping

Inductive thematic analysis of the literature identified revealed five overarching themes, which inform the development of a list of defining attributes of Care Biography. The theme of *Meaningfulness and Existential Coping* (i.e., helping a patient to consolidate their sense of identity and what matters to them) frequently emerges from applications of a 'biographical approach' across multiple care contexts. In the context of palliative care, according to Lindqvist et al. (2015), biographical approaches are 'recognised as having profound therapeutic potential in a variety of ways, with the common denominator of assisting people to create meaning through the act of storytelling' and constitute 'a nonpharmacological method for

addressing existential issues' (p. 41). They are also often associated with addressing conditions such as depression, distress, grief and loneliness, by enabling patients to gain a sense of meaning out of their condition (Hesse, Forstmeier, Mochamat, et al., 2019). In the context of aged and dementia care, Clarke (2000) points out that biographical approaches enable carers and patients 'to facilitate an assessment of the present, a re-evaluation of the past, and plans for the future' (p. 429). As was the case with palliative care, they also offer an alternative to medical and pharmacological approaches to dementia care (McGreevy, 2016).

When considering the purpose of ICU diaries, the theme of *Meaningfulness and Existential Coping* is the central theme. ICU diaries help patients to make sense of their time in ICU by filling in memory gaps, which can have significant therapeutic benefit, particularly in addressing psychological disturbances, notably, PTSD (Egerod & Bagger, 2010; Egerod et al., 2011; Ewens et al., 2015; Jones et al., 2010, 2012; Nielsen et al., 2018). Tavares et al. (2019) state that ICU diaries enable a patient to 'assign meaning and coherence and to chronologically order the period of time when memories are absent or distorted' (p. 165).

3.3.2 | Empathy and understanding

Clarke (2000) points out that biographical approaches in aged care often 'emphasise that the attitudes, interests, and desires of older people are the culmination of a lifetime of experiences' (p. 429), and as Pope (2012) points out, this enables care providers to 'discover the person behind the patient' (p. 35). Egerod et al. (2011) point out that ICU diaries describe patient illness 'in everyday language with a compassionate tone rather than the emotionally neutral and high-technology vernacular of conventional hospital journaling' (p. 1922). ICU diaries also help to facilitate dialog and communication between care providers, patients, and family members. For example, in a study by Aitken et al. (2017), ICU diaries were found to be a 'tool to promote communication between health care workers and family' (p. 276). Similarly, according to Nielsen et al. (2018), 'diaries co-authored by relatives and staff have been shown to facilitate information and communication between staff and relatives... making ICU staff better understand relatives' vulnerability' (p. 2). In another study by Nielsen et al. (2019), it was stated that ICU diaries not only 'help patient and relatives to discuss, compare and share their ICU experiences' but also enables ICU nurses to 'move from a technical focus to more personal involvement as the patient recovers' (p. 1297). The theme of *Empathy and Understanding* is also an important part of education and training for healthcare professionals, a point highlighted in McMillan's (2011) commentary.

3.3.3 | Promoting positive relationships

This theme emerged frequently in papers that discussed biographical approaches in aged and dementia care. For example, in a systematic

review by Menn et al. (2020) it is stated that 'biographical approaches in care facilities conducted in groups can provide support and improve relationships, preventing the feeling of loneliness... and potentially leading to an improved QoL' (p. 2). Such approaches often involve specific interventions such as the creation of memoirs or life story books facilitated by care providers, which according to Pouchly et al. (2013) can be done 'collaboratively with the individual, or with their close family and friends' (p. 117). Day and Wills (2008) point out that the creation of life story books 'increases socialisation for those involved by communicating, sharing and listening to stories' (p. 23). In the context of palliative care, the theme of *Promoting Positive Relationships* is closely aligned with the themes of *Meaningfulness and Existential Coping*, and *Empathy and Understanding*. These alignments are highlighted by Beasley et al. (2015) and also by Hesse, Forstmeier, Cuhls, et al. (2019) who in their study describe the training of volunteers for a palliative care intervention as consisting of 'developing a trusting relationship with the patient, accompanying the patient and the family, providing psychosocial support, dealing with death and dying, facilitating communication and helping with social, ethical, and spiritual issues' (p. 2).

3.3.4 | Consideration of social and cultural contexts

The *Social and Cultural Contexts* in which care recipients are situated also emerges as a key theme. For example, in the context of palliative care, Lindqvist et al. (2015) states that 'biographical approaches generally rely on some form of life story, in which a set of relationships are explored between the person and his or her cultural milieu' (p. 41). In a study of blog narratives of people with dementia (and their carers), Kannaley et al. (2019) point out that illness narratives are 'simultaneously social and personal' and 'inform the identity and account for the experiences of the author' (p. 3073). Clarke (2000) states that 'the biographical approach views the later decades of life as a time of ongoing development and self-determination, rather than a time of withdrawal and disengagement from society' (p. 429). Surr (2006) points out that 'relationships with others, the broader social context in which individuals are situated and narrative and storytelling' (p. 1720), play a crucial role in biographical approaches to dementia care.

3.3.5 | Self-care

The theme of *Self-Care* emerged primarily in those articles that mentioned 'care diary' or more specifically, 'self-care diary'. The term 'self-care diary' often referred to a method or tool for obtaining information from patients as part of study methodology (e.g., the use of the SCD). However, there were also several papers that used the term to refer to interventions or resources for patient self-care for a range of conditions including asthma, type 2 diabetes (T2D), spinal muscular atrophy (SMA), oral health, cardiac health, type1 diabetes (T1D) during pregnancy, and back pain. For example, in a study by

Sabzghabae et al. (2012), a self-care diary was used as a resource to 'educate the patient about their asthma and its management' (p. 67). In a study by Zhu et al. (2021), patients with T2D were provided with a self-care diary that 'consisted of items assessing the three main components of self-care among patients with T2D: physical activity, eating behaviour, and medication compliance' (p. 33). In a study by Linden et al. (2018), pregnant women and young mothers with T1D were given a self-care diary 'for self-reported monitoring of blood glucose, insulin doses, diet, activities and daily mood measures' (p. 233). Interestingly, the notion of *Self-Care* emerging from all of the articles that mention 'self-care diary', is a highly individualistic and context or condition-specific notion. It did not include consideration of a patient's broader care network (including family members or friends) and only pertained to a limited range of care needs over a limited period of time associated with the duration of a particular condition or illness.

3.4 | Defining attributes of care biography

The theme of *Meaningfulness and Existential Coping* identified in the literature reiterates the importance of care that accords with a patient's personal goals, values, and identity. Thus, the concept of Care Biography can be understood as enabling a person to achieve a sense of meaning, purpose, and selfhood, in how they are cared for throughout their life. The theme of *Self-Care* from the literature implies that patients have an important role to play in their own care, reiterating the importance of a person's self-care capacity, capability, care preferences and care planning. These ideas highlight the centrality of self-care agency, a notion that is implicit across all three attributes of the CLCT definition of Care Biography but requires further explication and elaboration. Self-care agency refers to a person's ability to make decisions and act in ways that promote their health and well-being. Such an ability does not consist solely of a person's own capacities and capabilities. It is acquired over time through learning, development, and acquisition of resources, all of which are dependent on their environment, in particular, the various relationships they have with their broader care network (Lawless et al., 2021). Hence, self-care agency is a relational notion (Burkitt, 2015) and Care Biography can be understood as a tool to promote self-care agency.

A Care Biography that captures both relevant objective information (e.g., medical information, care history, care providers and care networks), and relevant subjective information (e.g., personal preferences, goals, values, and social and cultural identity) enables a deeper understanding of a patient's their care needs, which includes the *Social and cultural Contexts* that shape those care needs. This can then facilitate *Empathy and Understanding*, which can in turn promote *Positive Care Relationships* necessary for self-care agency. The literature continues to emphasise the role of quality interactions and communications in promoting positive care relationships across various care contexts (Allande Cussó et al., 2021, 2022; Feo et al., 2023; Kwame & Petrucka, 2021; Tieu & Matthews, 2024).

Biographical approaches to care and the use of instruments such as care-diaries, can facilitate such interactions and communications because they provide carers with a deeper understanding of the patient as a person. However, as our analysis revealed, such approaches and instruments may be limited in how much relevant information is captured. They also tend to be initiated, directed, and managed primarily by professional care staff, which limits the extent to which patients can be actively engaged in their own care and thus agents of their care. In contrast, a Care Biography is an instrument that captures all the relevant information about a patient and empowers them to actively engage with their broader care network to receive care that accords with their unique individual needs.

Based on the critical attributes of the CLCT definition of Care Biography and key themes from our analysis of the literature on related concepts, the defining attributes of Care Biography can be divided into two broad categories, namely, purpose and function of promoting self-care agency, and the narrative form and content of the relevant documentation (Table 3).

3.5 | Model cases and potential applications

Given the novelty of the concept of Care Biography, we did not identify any existing case examples in the literature that would constitute model cases. However, some of the related concepts analysed and discussed above are associated with applications that might constitute similar or borderline cases (we also describe some additional examples in the following section). Here, we outline several potential applications of Care Biography (in nursing theory, cardiovascular care, aged care, and cancer care), and potential applications for further exploration and testing in transitional care, and palliative and end of life care (Table 4). These examples were developed through discussion among all authors, each of whom has specific expertise in a particular research discipline and/or clinical field.

3.6 | Borderline, related and illegitimate cases

The examples of 'biographical approaches' to care, 'self-care diaries', and 'ICU diaries', may constitute related cases. The notion of a 'care diary' as a method or tool used to record specific health-related information over a specific period of time (which includes the SCD) does not relate to the concept of Care Biography and thus constitutes a borderline case. There are also other concepts and examples that do not qualify as Care Biographies (or its application) but share some important similarities, and in particular, converge with the ethical and humanistic ethos underpinning Care Biography. For example, 'narrative based medicine' advocates for the integration of objective empirical evidence with subjective clinical expertise linked to a narrative and hermeneutical understanding of a patient's lived experience of illness and associated holistic care needs (Greenhalgh & Hurwitz, 1999; Greenhalgh, 1999). Similarly, 'narrative nursing'

TABLE 3 Defining attributes of care biography.

Purpose and function	Form and content
<ul style="list-style-type: none"> • Promotes self-care agency (where agency is understood in a relational sense). • Enables a deeper understanding of the patient to promote positive care relationships. • Guides comprehensive, holistic, and personalised care in various contexts and settings over extended periods of time. • Enables the patient and carer(s) to anticipate, plan for, and address care needs that arise in future. 	<ul style="list-style-type: none"> • Describes a patient's self-care capability and capacity and care preferences. • Describes a patient's care relationships and care networks. • Contains relevant objective and subjective information about the patient and their sociocultural background. • Contains a retrospective record of, and a prospective guide to, care provision. • Primarily takes the form of a cohesive narrative that is owned by the patient but co-created and endorsed by both patient and carer(s).

describes how nurses can engage in dialog or story telling about meaningful nurse–patient relationships as part of training and professional development. It enables them to develop and foster a narrative understanding of a patient's lived experience of illness and care needs and equips them with the skills to elicit patient perspectives on health and illness, which enables them to tailor care provision accordingly (Fitzpatrick, 2021). These ideas converge on the notion of 'digital story telling', which describes a knowledge translation (KT) method to promote a more comprehensive understanding of patient perspectives, lived experience, and holistic care needs through the creation of multi-media presentations (e.g., video clips). The process enables greater consumer engagement and shared decision making (Park et al., 2021; Pu et al., 2022). A key point on which these examples converge with Care Biography is the need to shift away from a unidirectional approach in how care-related information is applied in care practice, to a bidirectional approach in which care-related information from both care providers and patients is applied in care practice as part of a collaborative effort. Such a shift is necessary to ensure that care is appropriately individualised, meaningful, and patient directed, which is the primary goal of Care Biography application.

3.7 | Antecedents and consequences

The main antecedent of Care Biography is the capture of a broad range of patient biographical information (both objective and subjective) that informs subsequent care planning and provision. This may include information about disease, illness, developmental changes, life events, as well as a range of relevant biological, genetic, psychological, social, and cultural information. Such information is typically captured in various and often fragmented ways, both formally as part of healthcare systems and records, and informally as part of personal records (e.g., personal journals and social media profiles). The additional and perhaps most important antecedent is a conceptual one, namely, the recognition that such information can be integrated and compiled into a meaningful narrative to guide ongoing care planning and provision. While care plans draw from relevant patient biographical information, they are often focused narrowly on specific health outcomes and goals related to specific conditions over a defined period of time. Hence, they lack the degree of

personalisation, holistic integration, and temporal or diachronic integration that defines application of Care Biography. If the goal is to provide care that is appropriately patient or person-centred, then we need the conceptual and practical resources to provide carers with a deeper understanding of the patient and their care needs. This requires that relevant biographical information (objective and subjective) is used to inform care provision and confer on them a sense of ownership of their care. Thus, on the one hand, Care Biography provides us with a powerful conceptual tool to understand the complexities of patient or person-centred care, and on the other hand, it serves as a practical tool to help us improve the content and quality of care records and care plans. Genuine patient or person-centred care and self-care agency emerges as a consequence.

3.8 | Empirical referents

Empirical referents of Care Biography will consist of various ways in which Care Biographies are developed, constituted, and applied in practice where it will require multidisciplinary teams and care networks working together, communicating, coordinating, and assisting patients to navigate the challenges and complexities of their care journey. The model cases described in Table 4 capture a range of potential empirical referents that relate to the quality and form of the biographical information designed to inform subsequent care planning and provision. Care Biographies must be organised and structured as a coherent narrative capturing relevant biographical information and must also be meaningful to a patient, endorsed and owned by them. At the core of Care Biographies is the relationship between the patient and care professionals. There are tools being developed to measure such empirical referents (Conroy et al., 2023; Pinero de Plaza et al., 2023).

4 | DISCUSSION

The concept analysis in this paper has enabled us to further develop and refine the CLCT definition of Care Biography to capture the relevant humanistic and ethical dimensions of care. A Care Biography typically takes the form of a living document that captures the ebb and flow of a patient's care needs over the life course. It enables the

TABLE 4 Model cases of application of care biography.

Disciplinary/clinical perspective	Model case of application of care biography
Nursing Theory and Humanistic Care (MT; TC; JL; RF; ML; APP; RAC; ALK)	<p>Adapting Electronic Health Records (EHRs) to incorporate relevant biographical information about patients – Such information will include:</p> <ul style="list-style-type: none"> – Personal goals and values – Cultural background and sensitivities – Religious and spiritual care needs – A patient's care network comprised of both professional care providers and informal carers (i.e., family, friends and social support network) Relevant biographical information entered into EHRs shall be reviewed and endorsed by patients and their care network.
Cardiovascular Care (JH)	<p>Person-centred care is a fundamental pillar of integrated cardiovascular care, which can be facilitated by incorporating the defining attributes of Care Biography into Clinical History Taking and Assessment. This would involve:</p> <ul style="list-style-type: none"> – Engagement with patients to identify needs, values, preferences, and self-care capability and capacity – Collaboration with patients to generate and manage their personalised care plan (e.g., incorporating activities regarding adherence, risk factor and lifestyle modification) – Redesign of conservative care practice models to promote self-care through proactive engagement with a patient's care network, requiring multidisciplinary collaboration and the use of digital technology to support this approach
Aged care (SG; KL; JL; ML; LPL)	<p>“My Wellbeing Journal” has been developed to facilitate personalised care planning and goal setting for people living with one or more chronic conditions (Lawless et al., 2023). The tool could help by:</p> <ul style="list-style-type: none"> – Providing a record of a person's health and wellbeing goals – Assisting with prioritising how a person's goals align with their self-care and the care they receive from others – Supporting conversations between the person, their caregivers, and healthcare team about their goals and preferences ‘My Wellbeing Journal’ exists in the form of a booklet but can be converted into a digital format. <p>Flinders Assistant for Memory Enhancement (FAME)—A one-stop digital platform developed to deliver nonpharmacological interventions to delay the onset of dementia and technologies to support daily living (e.g., image-based phone/video calls to connect with user's family and care network, calendar) for older adults with mild cognitive impairment.</p> <p>Further information on FAME: https://blogs.flinders.edu.au/caring-futures-institute/2019/11/19/digital-health-teams-solution-provides-day-to-day-support-for-memory-loss/ https://www.youtube.com/watch?v=ceU5czhMnhA</p> <p>FAME is being re-engineered to include a wider care network (or 'care ecosystem') involving of family, clinicians, friends, and broader social networks. It aims to enable clients to interact with their care networks to facilitate delivery and adherence to interventions tailored to their unique care needs. Additional stakeholders in the care network can be identified, and their unique role/s in empowering and supporting the client are developed and refined through co-creation.</p>
Transitional Care (AC)	<p>A model of care to promote continuity of care – A transitional and enrichment service between a local health network and residential aged care provider in South Australia is under development and awaiting further testing. The service involves:</p> <ul style="list-style-type: none"> – Extensive collaboration, consultation, and support between acute care staff and residential aged care staff – Integration of geriatric in-home programmes and transitional care programmes – A digital platform (VIVA) to facilitate and deliver the programme <p>Ongoing development and testing of the digital platform VIVA is taking place across all community services within a local health network and its divisions of Aged Care, Rehabilitation and Palliative Care. The application is designed to:</p> <ul style="list-style-type: none"> – Enable all services across divisions to work on patient and carer driven goal setting – Allow patients to be able to input information into VIVA itself (e.g., relevant biographical information determined by them) – Be accessed as part of any service they interact with across the divisions
Cancer Care (CT)	<p>There is growing awareness of the need for 'cancer navigators' to assist cancer patients to navigate the technical and logistical complexities across their care journey (Chan et al., 2023). Cancer Survivorship Care Plans (SCPs) have been used to support ongoing care and navigation for cancer survivors for approximately 20 years but require refinement to meet the complex</p>

TABLE 4 (Continued)

Disciplinary/clinical perspective	Model case of application of care biography
	<p>care needs of cancer patients and their carers. These documents comprise a treatment summary, follow-up care instructions, information on potential treatment related late effects and care needs of cancer survivors, and are co-developed by healthcare teams and patients—Cancer SCPs can be developed further to include:</p> <ul style="list-style-type: none"> - Relevant personal history including care needs, care received, lived experience of cancer and related illnesses - Information regarding the biographical disruption of a cancer diagnosis and its treatment - Information that enables a broad range of carers (both formal and informal) to provide personalised and holistic care for people living with and beyond cancer <p>A cancer survivorship care plan that incorporates the defining attributes of a Care Biography will:</p> <ul style="list-style-type: none"> - Enable professional care providers, people living with and beyond cancer (and their broader care network) to plan, support and navigate care across the cancer continuum and beyond - Contribute to integrated support for people living with and beyond cancer across acute care settings, primary care, community care, and social services
Palliative and End of Life Care (AC)	<p>Care Biographies enacted by interdisciplinary specialist palliative care teams have potential to support safe and high-quality palliative care in non-specialist palliative care contexts and settings. It offers potential to:</p> <ul style="list-style-type: none"> - Support patient's and informal carer's agency in matters of care, e.g., advance care planning and end of life decision making - Support informal carers in their roles and negotiations with health services, and in integration of palliative care - Build relationships with the public health palliative care movement's agenda to promote death literacy, highlighting matters of sociocultural and community importance (as opposed to matters of clinical importance framed in biomedicine)

patient and their carers to develop a care plan that integrates prior care history with future care trajectories in a comprehensive, holistic, and personalised form. A thoroughly comprehensive Care Biography would capture relevant information from the moment of birth (or perhaps even during gestational development) all through to the end of life. This would encompass a range of objective information (e.g., medical information, care history, care providers and care networks), and subjective information (e.g., personal preferences, goals, values, and social and cultural identity). It would also serve as a repository of personal reflections on the experiences and challenges faced throughout a patient's care journey. The information would be integrated across time in meaningful and appropriate ways to constitute a cohesive narrative developed and endorsed by both patients and their carers. It would capture the way in which a person and their care needs change over the life course and how those changes are linked to relevant care networks, transitions, and trajectories. It would be owned by the patient and used by them in conjunction with their carer(s) and care network to negotiate care at various stages of life and in response to various changes in health and care needs throughout their life. Previous studies have shown that adverse events or reactions linked to care provision could have been avoided if staff had more information about the patient (Andersson et al., 2015; Van Gaal et al., 2014). Thus, it could also capture relevant information to ensure that such adverse events or reactions can be avoided in future.

A Care Biography also captures the crucial role that care networks play throughout a person's life, not only in assisting them with their care needs but also in helping them navigate various

complexities and logistical challenges. Meeting a person's care needs requires assistance from an extended care network that includes multidisciplinary teams over an extended period of time, something that has only been recently recognised, for example, through calls for more integrated care and specialist navigators to work with patients over an extended care journey (Bulto et al., 2024; Chan et al., 2023; Gallagher et al., 2022) and applications of patient journey mapping (Bulto, Davies, et al., 2024; Joseph et al., 2023; Ly et al., 2021). A Care Biography is thus a diachronic or temporally integrated representation of the patient, their care needs, and their care network, and can facilitate greater focus on integrated and continuous (rather than episodic) approaches to care provision over extended periods of time. It promotes a more holistic and humanistic conceptualisation of the patient, one that upholds their identity and agency, and thus enables both patients and carers to be in the best position to plan care that is appropriately person-centred. Ultimately, it challenges our existing assumptions and ideas around care and its goals, and situates it within a philosophical framework that enables the practice of care to be more explicitly and effectively geared towards promoting 'the good life'.

4.1 | Limitations of study

While our literature review was comprehensive with regard to the range of databases searched and selection of relevant search terms, we note that there were several other search terms identified from our initial typography that were not included in our search and

analysis, such as 'care narrative', 'care passport' and 'personalised care plan'. To include one or more of those terms and associated literature would go beyond the scope of the current concept analysis without necessarily contributing further to its aims. However, it is possible that additional literature may contain concepts closely related to Care Biography that can further inform our concept analysis and perhaps provide additional related or actual cases of Care Biography and its application.

5 | CONCLUSION

There is growing need and support for ways to capture the biographical and lived experiences of patients more consistently and accurately, particularly through the use of emerging digital and information technologies. The concept of Care Biography is novel in the health and care literature, only described in part, but can serve as a powerful tool for this purpose. It promotes a deeper, and more integrated and holistic understanding of care needs over their life course, facilitating care planning and decision making, and ultimately empowering patients to be in control of how they are cared for throughout their life. It helps transform healthcare into a collaborative and empathetic journey, where patients are active agents in their care and where their unique personal, social, and cultural identities come to the fore. Ultimately, it provides an important conceptual and practical tool to achieve and uphold the ethical and humanistic ideals of care amidst increasing application of digital and information technologies in care provision.

ACKNOWLEDGMENTS

This work was not supported by any funding. Open access publishing facilitated by Flinders University, as part of the Wiley - Flinders University agreement via the Council of Australian University Librarians.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Matthew Tieu  <https://orcid.org/0000-0003-3578-6579>

Regina Allande-Cussó  <https://orcid.org/0000-0001-8325-0838>

Maria A. Pinero de Plaza  <https://orcid.org/0000-0001-5421-9604>

REFERENCES

- Aitken, L. M., Rattray, J., Kenardy, J., Hull, A. M., Ullman, A. J., Le Brocque, R., Mitchell, M., Davis, C., Castillo, M. I., & Macfarlane, B. (2017). Perspectives of patients and family members regarding psychological support using intensive care diaries: An exploratory mixed methods study. *Journal of Critical Care*, 38, 263–268. <https://doi.org/10.1016/j.jcrrc.2016.12.003>
- Allande Cussó, R., Siles González, J., Ayuso Murillo, D., & Gómez Salgado, J. (2021). A new conceptualization of the nurse-patient relationship construct as caring interaction. *Nursing Philosophy*, 22(2), e12335. <https://doi.org/10.1111/nup.12335>
- Allande-Cussó, R., Fernández-García, E., & Porcel-Gálvez, A. M. (2022). Defining and characterising the nurse-patient relationship: A concept analysis. *Nursing Ethics*, 29(2), 462–484. <https://doi.org/10.1177/09697330211046651>
- Andersson, Å., Frank, C., Willman, A. M. L., Sandman, P. O., & Hansebo, G. (2015). Adverse events in nursing: A retrospective study of reports of patient and relative experiences. *International Nursing Review*, 62(3), 377–385. <https://doi.org/10.1111/inr.12192>
- Balint, E. (1969). The possibilities of patient-centered medicine. *The Journal of the Royal College of General Practitioners*, 17(82), 269–276.
- Beasley, E., Brooker, J., Warren, N., Fletcher, J., Boyle, C., Ventura, A., & Burney, S. (2015). The lived experience of volunteering in a palliative care biography service. *Palliative & Supportive Care*, 13(5), 1417–1425. <https://doi.org/10.1017/S1478951515000152>
- Brooker, D. (2007). *Person-centred dementia care: Making services better (Bradford Dementia Group good practice guide)*. Jessica Kingsley Publishers.
- Bulto, L. N., Davies, E., Kelly, J., & Hendriks, J. M. (2024). Patient journey mapping: Emerging methods for understanding and improving patient experiences of health systems and services. *European Journal of Cardiovascular Nursing*, 23(4), 429–433. <https://doi.org/10.1093/eurjcn/zvae012>
- Bulto, L. N., Roseleur, J., Noonan, S., Pinero de Plaza, M. A., Champion, S., Dafny, H. A., Pearson, V., Nesbitt, K., Gebremichael, L. G., Beleigoli, A., Gulyani, A., Schultz, T., Hines, S., Clark, R. A., & Hendriks, J. M. (2024). Effectiveness of nurse-led interventions versus usual care to manage hypertension and lifestyle behaviour: A systematic review and meta-analysis. *European Journal of Cardiovascular Nursing*, 23, 21–32. <https://doi.org/10.1093/eurjcn/zvad040>
- Burkitt, I. (2015). Relational agency: Relational sociology, agency and interaction. *European Journal of Social Theory*, 19(3), 322–339. <https://doi.org/10.1177/1368431015591426>
- Chan, R. J., Milch, V. E., Crawford-Williams, F., Agbejule, O. A., Joseph, R., Johal, J., Dick, N., Wallen, M. P., Ratcliffe, J., Agarwal, A., Nekhlyudov, L., Tieu, M., Al-Momani, M., Turnbull, S., Sathiaraj, R., Keefe, D., & Hart, N. H. (2023). Patient navigation across the cancer care continuum: An overview of systematic reviews and emerging literature. *CA: A Cancer Journal for Clinicians*, 73(6), 565–589. <https://doi.org/10.3322/caac.21788>
- Clarke, A. (2000). Using biography to enhance the nursing care of older people. *British Journal of Nursing*, 9(7), 429–433. <https://doi.org/10.12968/bjon.2000.9.7.6323>
- Conroy, T., Pinero de Plaza, M. A., Mudd, A., Mitchell, M., & Kitson, A. (2023). Measuring fundamental care using complexity science: A descriptive case study of a methodological innovation. *Journal of Clinical Nursing*, 32(11–12), 2903–2912. <https://doi.org/10.1111/jocn.15905>
- Day, M. R., & Wills, T. (2008). A biographical approach. *Nursing Older People*, 20(6), 22–24.
- Egerod, I., & Bagger, C. (2010). Patients' experiences of intensive care diaries—A focus group study. *Intensive & Critical Care Nursing*, 26(5), 278–287. <https://doi.org/10.1016/j.iccn.2010.07.002>
- Egerod, I., Christensen, D., Schwartz-Nielsen, K. H., & Agård, A. S. (2011). Constructing the illness narrative: A grounded theory exploring patients' and relatives' use of intensive care diaries. *Critical Care Medicine*, 39(8), 1922–1928. <https://doi.org/10.1097/CCM.0b013e31821e89c8>
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196(4286), 129–136. <https://doi.org/10.1126/science.847460>

- Ewens, B. A., Hendricks, J. M., & Sundin, D. (2015). The use, prevalence and potential benefits of a diary as a therapeutic intervention/tool to aid recovery following critical illness in intensive care: A literature review. *Journal of Clinical Nursing*, 24(9–10), 1406–1425. <https://doi.org/10.1111/jocn.12736>
- Feo, R., Conroy, T., Jangland, E., Muntlin Athlin, Å., Brovall, M., Parr, J., Blomberg, K., & Kitson, A. (2018). Towards a standardised definition for fundamental care: A modified Delphi study. *Journal of Clinical Nursing*, 27(11–12), 2285–2299. <https://doi.org/10.1111/jocn.14247>
- Feo, R., Young, J. A., Urry, K., Lawless, M., Hunter, S. C., Kitson, A., & Conroy, T. (2023). 'I wasn't made to feel like a nut case after all': A qualitative story completion study exploring healthcare recipient and carer perceptions of good professional caregiving relationships. *Health Expectations*, 27(1):e13871. <https://doi.org/10.1111/hex.13871>
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 80–92. <https://doi.org/10.1177/160940690600500107>
- Fitzpatrick, J. J. (2021). Narrative nursing: Empowering nurse leaders. *Nursing Administration Quarterly*, 45(4), 324–329. <https://doi.org/10.1097/naq.0000000000000486>
- Van Gaal, B. G. I., Schoonhoven, L., Mintjes-de Groot, J. A. J., Defloor, T., Habets, H., Voss, A., van Achterberg, T., & Koopmans, R. T. C. M. (2014). Concurrent incidence of adverse events in hospitals and nursing homes. *Journal of Nursing Scholarship*, 46(3), 187–198.
- Gallagher, C., Hendriks, J. M., Nyfort-Hansen, K., Sanders, P., & Lau, D. H. (2022). Integrated care for atrial fibrillation: The heart of the matter. *European Journal of Preventive Cardiology*, 29(15), 2058–2063. <https://doi.org/10.1093/eurjpc/zwaa065>
- Greenhalgh, T. (1999). Narrative based medicine: Narrative based medicine in an evidence based world. *BMJ*, 318(7179), 323–325. <https://doi.org/10.1136/bmj.318.7179.323>
- Greenhalgh, T., & Hurwitz, B. (1999). Narrative based medicine: Why study narrative? *BMJ*, 318(7175), 48–50. <https://doi.org/10.1136/bmj.318.7175.48>
- Halfon, N., Larson, K., Lu, M., Tullis, E., & Russ, S. (2014). Lifecourse health development: Past, present and future. *Maternal and Child Health Journal*, 18(2), 344–365. <https://doi.org/10.1007/s10995-013-1346-2>
- Hesse, M., Forstmeier, S., Cuhls, H., & Radbruch, L. (2019). Volunteers in a biography project with palliative care patients – A feasibility study. *BMC Palliative Care*, 18(1), 79. <https://doi.org/10.1186/s12904-019-0463-0>
- Hesse, M., Forstmeier, S., Mochamat, M., & Radbruch, L. (2019). A review of biographical work in palliative care. *Indian Journal of Palliative Care*, 25(3), 445–454. https://doi.org/10.4103/IJPC.IJPC_16_19
- Jones, C., Backman, C., Capuzzo, M., Egerod, I., Flaatten, H., Granja, C., Rylander, C., & Griffiths, R. D., The RACHEL group. (2010). Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: A randomised, controlled trial. *Critical Care*, 14(5), R168. <https://doi.org/10.1186/cc9260>
- Jones, C., Bäckman, C., & Griffiths, R. D. (2012). Intensive care diaries and relatives' symptoms of posttraumatic stress disorder after critical illness: A pilot study. *American Journal of Critical Care*, 21(3), 172–176. <https://doi.org/10.4037/ajcc2012569>
- Joseph, A. L., Monkman, H., Kushniruk, A., & Quintana, Y. (2023). Exploring patient journey mapping and the learning health system: Scoping review. *JMIR Human Factors*, 10, e43966. <https://doi.org/10.2196/43966>
- Kannaley, K., Mehta, S., Yelton, B., & Friedman, D. B. (2019). Thematic analysis of blog narratives written by people with Alzheimer's disease and other dementias and care partners. *Dementia*, 18(7/8), 3071–3090. <https://doi.org/10.1177/1471301218768162>
- Kitson, A., Feo, R., Lawless, M., Arciuli, J., Clark, R., Golley, R., Lange, B., Ratcliffe, J., & Robinson, S. (2022). Towards a unifying caring life-course theory for better self-care and caring solutions: A discussion paper. *Journal of Advanced Nursing*, 78(1), 6. <https://doi.org/10.1111/jan.14887>
- Kitwood, T. M., & Brooker, D. (2019). *Dementia reconsidered, revisited: The person still comes first* (2nd ed.). Open University Press.
- Kwame, A., & Petruca, P. M. (2021). A literature-based study of patient-centered care and communication in nurse-patient interactions: Barriers, facilitators, and the way forward. *BMC Nursing*, 20(1), 158. <https://doi.org/10.1186/s12912-021-00684-2>
- Lawless, M. T., Archibald, M. M., Ambagtsheer, R. C., Pinero de Plaza, M. A., & Kitson, A. L. (2023). My wellbeing journal: Development of a communication and goal-setting tool to improve care for older adults with chronic conditions and multimorbidity. *Health Expectations*, 27(1):e13890. <https://doi.org/10.1111/hex.13890>
- Lawless, M. T., Tieu, M., Feo, R., & Kitson, A. L. (2021). Theories of self-care and self-management of long-term conditions by community-dwelling older adults: A systematic review and meta-ethnography. *Social Science & Medicine*, 287, 114393. <https://doi.org/10.1016/j.socscimed.2021.114393>
- Lawless, M. T., Tieu, M., Golley, R., & Kitson, A. (2024). How and where does “care” fit within seminal life-course approaches? A narrative review and critical analysis. *Journal of Advanced Nursing*, 80, 871–883. <https://doi.org/10.1111/jan.15852>
- Linden, K., Berg, M., Adolfsson, A., & Sparud-Lundin, C. (2018). Person-centred, web-based support in pregnancy and early motherhood for women with type 1 diabetes mellitus: A randomized controlled trial. *Diabetic Medicine*, 35(2), 232–241. <https://doi.org/10.1111/dme.13552>
- Lindqvist, O., Threlkeld, G., Street, A. F., & Tishelman, C. (2015). Reflections on using biographical approaches in end-of-life care: Dignity therapy as example. *Qualitative Health Research*, 25(1), 40–50. <https://doi.org/10.1177/1049732314549476>
- Ly, S., Runacres, F., & Poon, P. (2021). Journey mapping as a novel approach to healthcare: A qualitative mixed methods study in palliative care. *BMC Health Services Research*, 21(1), 915. <https://doi.org/10.1186/s12913-021-06934-y>
- McCance, T., McCormack, B., & Dewing, J. (2011). An exploration of person-centredness in practice. *OJIN: The Online Journal of Issues in Nursing*, 16(2), 1.
- McCormack, B. (2004). Person-centredness in gerontological nursing: An overview of the literature. *Journal of Clinical Nursing*, 13(3a), 31–38. <https://doi.org/10.1111/j.1365-2702.2004.00924.x>
- McGreevy, J. (2016). Arts-based and creative approaches to dementia care. *Nursing Older People*, 28(1), 20–23.
- McMillan, P. W. (2011). Understanding what it means to be a health practitioner: Biographies of care and concern. *The Clinical Teacher*, 8(3), 205–207. <https://doi.org/10.1111/j.1743-498X.2011.00462.x>
- Menn, L., Corsten, S., Lauer, N., & Wallace, S. J. (2020). The effectiveness of biographical approaches in long-term care: A systematic review. *The Gerontologist*, 60(4), e309–e328. <https://doi.org/10.1093/geront/gnz074>
- Miller, M., Taylor, A., Wells, M., Roe, L., Hagen, S., Parson, F., Newlands, L., Galbraith, F., Paterson, G., & Kearney, N. (2007). Health professionals' views of the feasibility and acceptability of an oral care diary by patients during chemotherapy. *European Journal of Oncology Nursing*, 11(1), 82–84. <https://doi.org/10.1016/j.ejon.2006.02.006>
- Nail, L. M., Jones, L. S., Greene, D., Schipper, D. L., & Jensen, R. (1991). Use and perceived efficacy of self-care activities in patients receiving chemotherapy. *Oncology Nursing Forum*, 18(5), 883–887.
- Nielsen, A. H., Angel, S., Egerod, I., & Hansen, T. B. (2018). The effect of diaries written by relatives for intensive care patients on post-traumatic stress (DRIP study): Protocol for a randomized controlled trial and mixed methods study. *BMC Nursing*, 17, 37. <https://doi.org/10.1186/s12912-018-0306-y>
- Nielsen, A. H., Angel, S., Hansen, T. B., & Egerod, I. (2019). Structure and content of diaries written by close relatives for intensive care unit

- patients: A narrative approach (DRIP study). *Journal of Advanced Nursing*, 75(6), 1296–1305. <https://doi.org/10.1111/jan.13956>
- Park, J. O., Webb, C. E., & Temple-Oberle, C. F. (2021). Supporting women's BIA-ALCL decision-making: Role of the individual consult in empowering the patient-physician team. *Plastic and Reconstructive Surgery Global Open*, 9(10), e3843. <https://doi.org/10.1097/GOX.0000000000003843>
- Pinero de Plaza, M. A., Yadav, L., & Kitson, A. (2023). Co-designing, measuring, and optimizing innovations and solutions within complex adaptive health systems. *Frontiers in Health Services*, 3, 1154614. <https://doi.org/10.3389/frhs.2023.1154614>
- Pope, T. (2012). How person-centred care can improve nurses' attitudes to hospitalised older patients. *Nursing Older People*, 24(1), 32–37. <https://doi.org/10.7748/nop2012.02.24.1.32.c8901>
- Pouchly, C. A., Corbett, L. H., & Edwards, K. (2013). Life story work – Overcoming issues of consent and confidentiality. *Quality in Ageing and Older Adults*, 14(2), 116–127. <https://doi.org/10.1108/14717791311327060>
- Pu, D., Bonnici, R., Shorr, R., & Haines, T. (2022). Digital storytelling to facilitate consumer engagement in healthcare research. *Health Promotion Journal of Australia*, 33(3), 758–767. <https://doi.org/10.1002/hpja.565>
- Rogers, C. R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology*, 21(2), 95–103. <https://doi.org/10.1037/h0045357>
- Ryan, T. (2022). Facilitators of person and relationship-centred care in nursing. *Nursing Open*, 9(2), 892–899. <https://doi.org/10.1002/nop2.1083>
- Sabzghabae, A., Balasubramanian, R., Bhojan, C., Devarajan, V., Shanmugam, S., Varughese, J., Nair, M. S., & Velu, S. (2012). Pharmaceutical care for asthma patients: A developing country's experience. *Journal of Research in Pharmacy Practice*, 1(2), 66–71. <https://doi.org/10.4103/2279-042X.108373>
- Sharp, L., Laurell, G., Tiblom, Y., Andersson, A., & Birksjö, R. M. (2004). Care diaries: A way of increasing head and neck cancer patient's involvement in their own care and the communication between clinicians. *Cancer Nursing*, 27(2), 119–126. <https://doi.org/10.1097/00002820-200403000-00004>
- Stewart, M. (2001). Towards a global definition of patient centred care. *BMJ*, 322(7284), 444–445. <https://doi.org/10.1136/bmj.322.7284.444>
- Surr, C. A. (2006). Preservation of self in people with dementia living in residential care: A socio-biographical approach. *Social Science & Medicine* (1982), 62(7), 1720–1730. <https://doi.org/10.1016/j.socscimed.2005.08.025>
- Tavares, T., Camões, J., Carvalho, D. R., Jacinto, R., Vales, C. M., & Gomes, E. (2019). Assessment of patient satisfaction and preferences with an intensive care diary. *Revista Brasileira de Terapia Intensiva*, 31(2), 164–170. <https://doi.org/10.5935/0103-507X.20190028>
- Tieu, M. (2021). Truth and diversion: Self and other-regarding lies in dementia care. *Bioethics*, 35(9), 857–863. <https://doi.org/10.1111/bioe.12951>
- Tieu, M., & Kitson, A. L. (2023). Care depersonalized: The risk of infocratic “personalised” care and a posthuman dystopia. *The American Journal of Bioethics*, 23(9), 89–91. <https://doi.org/10.1080/15265161.2023.2237472>
- Tieu, M., & Matthews, S. (2024). The relational care framework: Promoting continuity or maintenance of selfhood in person-centered care. *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, 49(1), 85–101. <https://doi.org/10.1093/jmp/jhad044>
- Tresolini, C. P. (1994). Health professions education and relationship-centered care: Report. Pew Health Professions Commission, UCSF Center for the Health Professions.
- Walker, L. O., & Avant, K. C. (2019). *Strategies for theory construction in nursing* (6th ed.). Pearson.
- Yahaya, N. A., Subramanian, P., Bustam, A. Z., & Taib, N. A. (2015). Symptom experiences and coping strategies among multi-ethnic solid tumor patients undergoing chemotherapy in Malaysia. *Asian Pacific Journal of Cancer Prevention*, 16(2), 723–730. <https://doi.org/10.7314/apjcp.2015.16.2.723>
- Zhu, B., Feng, T., & Izci-Balserak, B. (2021). Using research electronic data capture for longitudinal assessment among older adults with diabetes enhances real-time data collection. *CIN: Computers, Informatics, Nursing*, 39(1), 32–41. <https://doi.org/10.1097/CIN.0000000000000641>

How to cite this article: Tieu, M., Allande-Cussó, R., Collier, A., Cochrane, T., Pinero de Plaza, M. A., Lawless, M., Feo, R., Perimal-Lewis, L., Thamm, C., Hendriks, J. M., Lee, J., George, S., Laver, K., & Kitson, A. (2024). Care biography: A concept analysis. *Nursing Philosophy*, 25, e12489. <https://doi.org/10.1111/nup.12489>