Fostering Compassionate Care in Long-Term Care Settings

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Abstract

Compassion is recognized as a catalyst for quality in healthcare. While the empirical study of compassion in healthcare has been facilitated by the emergence of the Sinclair Compassion Questionnaire (SCQ), its patient-reported design precludes its use among patients whose conditions prevent them from answering questions about the care they receive. This presents a particular barrier to compassion research in long-term care settings, where the prevalence of cognitive impairment is high, and increasing (Ng et al., 2020). Informal care-partners may be the sole source of information about compassionate care in these settings, but no tool is currently available to measure this construct from that perspective. To address this gap, this research sought to validate a new version of the Sinclair Compassion Questionnaire (SCQ-CP) which has been semantically adapted for use with care-partners. In the first phase of the study, the SCQ-CP was administered to a pilot sample of care-partners using Collin's pre-testing framework (2003) to verify that the tool is comprehensible, acceptable, and user-friendly. In the second phase of the study, samples of individual care-partners and care-partner/resident dyads were recruited. Care-partners completed two questionnaire batteries, separated by a delay of 30 days. The first battery consisted of the SCQ-CP and the Canadian Health Care Evaluation Project (CANHELP) Lite Long-Term Care Questionnaire; the second, the SCQ-CP alone. Residents completed a single questionnaire battery consisting of the original SCQ. Statistical analyses evaluated internal consistency, convergent validity, SCQ/SCQ-CP congruence, and test-retest reproducibility. Results provided initial support for the use of the SCQ-CP as a psychometrically-sound measure of compassionate care in long-term care settings, thereby enabling further research on compassionate care in a setting that was previously out of reach.

Dedication

To my dear family, and to my friends, whose unconditional love and support have made this journey possible.

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Fostering Compassion in Long-Term Care Settings

Introduction

The idea of compassion, which means "to suffer with," has been a perennial object of human contemplation for millennia. Commonly held as a fundamental aspect of the human condition (Kanov et al., 2004), the prominence of compassion in the spiritual and philosophical discourse transcends time and culture, its threads being found in the social and ethical fabric of traditions as geographically and chronologically diverse as the Bantu, the Confucian, the Buddhist, the Stoic, the Judeo-Christian, and others (Hawkins & Nadel, 2022; Soto-Rubio & Sinclair, 2018). Compassion scholarship traverses a similarly wide range of disciplines, among others theology, ethics, biology, sociology, anthropology, and psychology. Each of these traditions and fields have examined and developed the idea of compassion within their unique contexts—a situation that, combined with the effects of time and language, has made the construct of compassion at once highly intuitive and notoriously challenging to define.

With a written record that reaches back to Antiquity, it may be tempting to conceptualize compassion as a purely social or ideological construct manufactured by prophets, philosophers, or kings as an ideal to which one should aspire. Indeed, for the people of Ancient Greece, the idea of compassion connoted a form of metaphysical connection between oneself, all of creation, and the divine; a spiritual conceptualization that perseveres in a wide range of contemporary religious communities (Soto-Rubio & Sinclair, 2018). While compassion, with its altruistic and self-effacing properties, finds a fitting home in the spiritual and ethical discourses as a *virtue*, it has also been the object of considerable empirical thought as a biologically grounded, evolutionary adaptation.

In their evolutionary analysis and empirical review, Goetz and colleagues (2010) defined compassion as "an affective state that is oriented toward enhancing the welfare of those who suffer" and report three non-mutually exclusive evolutionary theories for compassion (p.354). First, they present the argument that compassion emerged because such an affective orientation improved the odds of infant survival. Adults who were attuned to the needs of their dependents were more likely to tend to their offspring until they reached independence and could themselves reproduce. Second, they present a related argument that compassion emerged on the basis of being an attractive quality for the selection of a sexual partner. To reproduce with a compassionate partner, the authors report, is to invest resources into a relationship that is more likely to feature affection, protection, and cooperation. The third argument presented is that, within the context of an increasingly complex social environment, compassion engendered cooperation with individuals who are not linked by blood. Compassion-oriented individuals and communities would be, by this logic, more likely to survive internal and external existential threats. Given these compelling theories, Goetz and colleagues make the case for a conceptualization of compassion as a naturally selected characteristic that emerged independently of, and is distinct from, other emotions with which it is often categorized or conflated.

Semantic Considerations

While compassion, with its roots in early human biology and thought, is considered a defining feature of the human condition (Himmelfarb, 2001), its definition is notoriously elusive. Ancient and abstract, the words used to encapsulate the idea of compassion, the ways those words have been interpreted (and translated), and the relationships that exist between those words, have shifted over the course of centuries. To arrive at a clearer understanding of

compassion as it is understood today, it may be helpful to trace its terminological development across time, to identify related terms and their intersections, and ultimately, to distinguish between them. In the sections below, we explore the intertwining etymological and semantic histories of sympathy, empathy, and compassion.

Sympathy

A combination of the prefix *sym* (together) and the noun *pathe* (affection), the term sympathy comes from the ancient Greek *sympatheia*, which means "to suffer with." Sympathy was originally used to articulate the idea of an intangible, metaphysical matrix that links an object or individual with the rest of creation, such that the actions or outcomes of one part of existence may be felt by another part of existence, even in the absence of any apparent physical link (Soto-Rubio & Sinclair, 2018). This notion of an imperceptible connection between disparate entities would later lose its cosmic connotation when it was adopted for use in the biomedical discourse, where from the 2nd century it was used to explain the tendency for some diseases to spread to different parts of the body. This use of the word sympathy fell into disuse and in the 16th century was repurposed to describe the human capacity to feel the emotional experience of another person. The term was leveraged, particularly by thinkers in the Anglosphere during the Industrial Revolution (Himmelfarb, 2001), to promote charitable and progressive causes, a co-opting that distorted sympathy's originally egalitarian connotation and replaced it with one that places the sympathizer on higher moral or social footing in relation to the person who is afflicted. This modification remains essential to our contemporary understanding of sympathy: an affective experience characterised by the feeling of pity or sorrow for the circumstances of an outsider.

Empathy

In contrast to the ancient heritage of sympathy, it is as recently as the 19th century that empathy emerged into the lexicon (Soto-Rubio & Sinclair, 2018). The term was coined by German philosopher Robert Vischer to articulate the capacity for "feeling *in*", that is to say, the ability to cognitively enter into the context of an external entity, and in doing so, arrive at a deeper understanding of oneself and the larger human condition. Originally conceived as a purely cognitive phenomenon, the term later developed an affective element akin to egalitarian sympathy. The rational and emotional duality of empathy crystalized into our contemporary understanding of empathy: a cognitive and affective experience characterized by vicarious understanding of the circumstances and feelings of an outsider.

Compassion

Common etymologies, overlapping connotations, and gradual vernacular shifts have produced a lexical ecosystem in which sympathy, empathy and compassion are regularly used synonymously to describe a state of shared feeling, shared experience, or some combination of the two. Unfortunately, this interchangeability is as prevalent in the empirical literature as it is in everyday speech, a state of affairs that has hindered the development of the field (Sinclair, Norris, et al., 2016). Despite this common practice, recent research has demonstrated that sympathy, empathy and compassion carry nuances that allow individuals not only to distinguish one from the other, but also to assign to them discrete levels of preference or esteem. In a grounded theory analysis of semi-structured interviews with 53 advanced cancer patients, Sinclair and colleagues (2017) found that sympathy was regarded by recipients of palliative care as a distant, impersonal, and self-serving expression of pity that was both unhelpful and unwelcome. The sample described empathy as a proximal, personal, and other-oriented recognition of suffering, coupled with an attempt to understand the experience of suffering from

the perspective of the sufferer. Empathy, in contrast to sympathy, was welcomed and appreciated by study participants. Participants reserved their highest regard, however, for compassion, which they characterised as an expression that extends, elevates, or amplifies the qualities of empathy through unconditional love, self-sacrifice and, crucially, action.

The findings of the aforementioned study reveal that while sympathy, empathy and compassion are related terms that are often conflated, they are not one and the same in practice. Sympathy is distinguished from empathy and compassion by its unique dislike by care recipients, as well as by its self-centred focus, impersonal glaze, and aversion to intimacy. While empathy and compassion are more difficult to parse due both to their common appreciation by care recipients and to their shared qualities such as a patient-centred focus, a desire to understand the experience and emotions of the other, and an approach-orientation, compassion entails an active engagement in the alleviation of suffering, a behavioural aspect that empathy lacks (Von Dietze & Orb, 2000). With these differences in mind, it would seem that whereas sympathy is a purely affective experience, and whereas empathy enlists both affective and cognitive mental resources, compassion integrates the affective, cognitive, and behavioural components of the human experience, a state of psychological harmony akin to the Rogerian concept of *congruence*, which he considered the condition that catalyzes a person-centred therapeutic relationship (Rogers, 1966).

Compassion in Healthcare: Why does it matter?

Patient Considerations

Compassion entails an active engagement in the alleviation of suffering, an exercise that is inherently compatible with the therapeutic mission of healthcare systems and providers. If compassion is predicated in suffering, it follows that the need for and delivery of compassion

should be most pronounced in settings of concentrated pain, illness, and infirmity. With respect to the need for compassion in healthcare settings, research suggests that patient populations regard compassion as a crucial component of high-quality care. When asked to describe "Good Quality Care", a sample of patients and care-partners preferred healthcare providers who exemplified humanist traits over those who exemplified technical skills (Attree, 2001), a finding that is further supported by observational research showing that patient satisfaction ratings are highest for primary care physicians who employ a patient-centred approach when compared to those who employ biopsychosocial, biomedical, and control-focused approaches (Flocke et al., 2002). A sample of 440 end-of-life patients endorsed respect and compassion as the fifth most important marker of care on a questionnaire of 28 elements related to quality end-of-life care (Heyland et al., 2006). A more recent Australian study found compassion to be one of the most valued healthcare provider traits by a sample of non-English speaking hospital patients and care partners (Garrett et al., 2008), a finding that highlights compassion's potential value as a care facilitator in multicultural healthcare environments (Singh et al., 2018). The apparent emphasis placed by patients in their evaluations of healthcare quality is mirrored by similar findings with family members of patients. When asked about how to improve the delivery of end-of-life care in Veterans Affairs Medical Centres, compassion emerged as the most common recommendation forwarded by bereaved next-of-kin (Riggs et al., 2014).

The literature unequivocally communicates that service users and their loved ones assign high value to compassion in healthcare, such that this appraisal has been qualified as a generally accepted notion (O'Toole et al., 2021). Perhaps the most compelling evidence in support of the argument that compassion is a definitive ingredient of high-quality healthcare comes from a recent study by Boss and colleagues, which analysed ratings of acute care experience, overall

quality of care, and compassion from 4,501 recent recipients of care at 14 urban and regional hospital Emergency Departments in Alberta, Canada. Stepwise hierarchical linear multiple regression revealed compassion to have the strongest association with ratings of overall care (Boss et al., 2024). With compassion alone accounting for nearly 20% of rating variance, the authors highlighted the absence of that metric from existing measures of care quality and called for its formal integration. Patients and care partners want and expect compassion from their healthcare providers and healthcare systems, and its presence is a robust explanatory variable of service user ratings of quality of care. While the *perception* of compassion in healthcare is important in-itself, the true value of compassion may reside it its impact on key indicators of patient well-being. An early review of the physician-patient relations literature found that an empathic physician communication style during history-taking significantly decreased emotional distress in patients and hastened symptom resolution (Stewart, 1995). A randomised pre-test/post-test control group study found that state-trait anxiety scores were significantly lower among women who viewed a 40-second video recording of a compassionate physician-patient exchange when compared with those who viewed a "standard" clinical exchange of equal duration (Fogarty et al., 1999). A retrospective study of 20,000 patients with type 1 or type 2 diabetes mellitus found high physician scores on a self-rated measure of clinical empathy was associated with 41 percent lower odds of hospitalization for disease complications (Del Canale et al., 2012). In a study with a healthy volunteer sample, both verbal and nonverbal compassionate communication interventions from a healthcare practitioner were found to significantly decrease heart rate, a finding that led Shaltout and colleagues (2012) to suggest that the delivery of compassion in healthcare settings may be therapeutic in itself. A more recent interpretive analysis of interviews of a small sample of healthcare recipients with mental health diagnoses led Bond

and colleagues (2024) to conclude that compassion is beneficial to mental health recovery, fosters hope in service users, and engenders healing.

Provider Considerations

The impact of compassion in healthcare settings is felt not only by service recipients and their loved ones, but by service providers as well. Clinical communication behaviours that demonstrate compassion, such as the use of humour, encouragement of patient participation, checking understanding, and educating patients about what to expect during their appointments, were found to distinguish between primary care physicians with and without prior malpractice claims (Levinson et al., 1997). An online cross-sectional survey of more than 1,000 physicians, nurses and allied healthcare professionals found that self-rated ability to deliver compassionate care was associated with the degree to which the corporate values of their employer aligned with their own (Pavlova et al., 2023). Importantly, healthcare providers who worked within organizations whose values were in harmony with their own not only felt more able to work compassionately with their patients, but were also more satisfied with their work, experienced less burnout, were both less likely to take non-vacation related time away from their roles, and less inclined to contemplate early retirement. This research is part of a growing body of evidence that challenges the empirical basis for the assumption that the exercise of compassion accelerates provider burnout. A meta-narrative review of the topic found that the compassion fatigue discourse lacked construct validity due to the regular conflation of compassion with related terms such as pity, sympathy, and empathy. In that review, Sinclair and colleagues (2017) uncovered no support for the popular assertion that highly compassionate care providers are predisposed to compassion fatigue, and as a result called for a critical re-conceptualization of the term as “compassion distress”, characterised as an occupational stress response that is triggered by the

obstruction of compassion, rather than by its delivery. This proposal reinforces earlier research which suggests that compassion may coincide with what some physicians consider a state of harmony between self and practice (Graber & Mitcham, 2004; Sinclair, Hack, et al., 2018), a condition that, rather than exposing healthcare providers to burnout, may actually protect them from it (Barsade & O'Neill, 2014; Soler-Gonzalez et al., 2017).

Organizational Considerations

Taking into account the mounting evidence linking compassion in healthcare to key indicators of patient and provider well being, it follows that some effects of compassion are experienced at the organizational and systemic levels. At the level of healthcare teams, the presence of compassion was described as a feature of workplace dynamics that allows carers themselves to feel cared for or looked after, an organizational quality that engendered a greater sense of worker confidence in their ability to meet the demands of their roles (Kahn, 1993), an overarching morale that can enhance the productivity and efficiency of organizations overall (Frost, 1999). The experience of compassion in the workplace was found by Lilius and colleagues (2003) to leave an enduring mark on affective and behavioural indicators of well-being, with compassion being associated with increased positive emotion and investment in work-related tasks, and decreased work-related stress, which in turn increased worker intentions to remain with their employer. Further analyses suggested that these conditions prompted a prosocial feedback loop whereby workers, themselves positively impacted by the experience of compassion in the workplace, make personal contributions to the compassionate ethos through behaviours such as mentorship, sharing of resources, and taking on additional tasks to support overwhelmed colleagues. Patient-centred care, a healthcare delivery modality that incorporates a number of behaviours closely related to compassion, such as developing a holistic understanding

of the patient as a person and taking the perspective of the patient, was associated with decreases in frequency of hospitalization, diagnostic testing orders, and specialist referrals (Bertakis & Azari, 2011).

Supply and Demand

Despite both its appraisal by patients, care partners, and practitioners as a cornerstone of quality care, and a growing body of evidence indicating the positive effect it has on measures of patient and practitioner health and well-being, research suggests that compassion in healthcare settings often does not meet needs or expectations. In their analysis of a small sample of first-visit oncology patient interview sessions, Easter and Beach (2004) found that resident and attending physicians acknowledged or responded adequately to 3 in 10 “clearly identified” opportunities for empathic engagement. A survey of 800 recently hospitalized patients found that only 53% endorsed the American health care system as one that generally provides compassionate care (Lown et al., 2011). A British qualitative study investigating the experiences of recently bereaved care partners of patients with dementia painted a healthcare landscape in which the delivery of compassion is possible but inconsistent, leading the authors to call for policy changes that would set a universal compassion standard (Crowther et al., 2013). In a very recent study on the experience of compassionate care among individuals living with a mental health condition, participants depicted psychiatric healthcare providers as often holding negative attitudes towards their patients, a situation that participants described as stigmatising and (re)traumatizing (Bond et al., 2024).

A Bellwether of Patient Treatment

The presence of compassion in healthcare is palpable, both qualitatively and quantitatively, to patients, families, providers, and the public at-large, but attention to its vital

place within the healthcare ecosystem is often most pronounced when it is absent. The Francis Report (2010, 2013) was published following an investigation into extraordinarily high mortality rates at an acute care regional hospital in the British Midlands and chronicles conditions of patient neglect and abuse summarized by Rafferty and Leary as "some of the most egregious failures in care joining the back catalogue of the worst atrocity stories in healthcare history" (2023, p. 3). The report implicates the absence of compassion as one of the factors that had set the stage for malpractice and misconduct, going so far as to describe a non-existent culture of listening to patients and the prioritization of financial concerns over quality of care and patient-centredness. Compassion is a prominent theme woven into the report's 290 recommendations, where it is described as a imperative practice to which all patients are entitled and which, to that end, must regain its places as a pillar of healthcare culture and objective of education, recruitment, training, and evaluation at every organizational level.

Scrutiny towards compassion in healthcare has come into even sharper focus in the wake of the COVID-19 pandemic, a public health crisis that has had a disproportionate impact on older adults in long-term care settings. In Australia, the recently concluded Royal Commission into Aged Care Quality and Safety identified 15 areas in which substandard care occurred. The report highlighted organizational focus on financial performance as a systemic problem in the aged care sector that reduced healthcare to a transaction characterized by provider-patient disconnection, lack of compassion, and unsafe care. Among the report's 148 recommendations, compassion features explicitly in recommendation 13, which lists compassion as a fundamental characteristic of high-quality care that must become a legislated standard of the Australian aged care system (Royal Commission into Aged Care Quality and Safety, 2021). Similarly, in the Canadian province of Ontario, the final report of a Long-Term Care COVID-19 inquiry chronicled the

failures of the long-term care system to adequately protect the health, well-being, and human rights of residents (and staff), and laid out a remedial vision for the future of long-term care as one that "must be grounded in respect, dignity, compassion and kindness for the people who live and work" within that system (Ontario's Long-Term Care COVID-19 Commission, 2021, p. 21). The final report emphasizes the critical role that leadership must play in the cultivation, promulgation, and embodiment of a workplace culture that is founded upon compassion and values, a recommendation that is echoed by research that has found compassion to be deficient among leaders in the long-term care sector and, ironically, a key to their success (O'Toole et al., 2021).

Establishment of the Compassion Construct and Model

Despite being an object of contemplation, admiration, and emulation for thousands of years, it is only relatively recently that compassion has been explored through a scientific lens. An early scoping review of the compassionate care literature conducted by Sinclair and colleagues (2016) uncovered only 44 articles over the 25-year period between 1988 and 2013, the vast majority of which were published after 2007. The authors noted that critical comparison between studies of compassion is hampered by the absence of a consistent operational definition, with studies regularly relying on preconceived conceptualizations that overlap with related terms, and definitions borrowed from dictionaries and theoretical publications that were limited in their applicability to clinical settings. Crucially, the authors remarked that this impediment to a coherent, empirical understanding of compassion in healthcare was exacerbated by the conspicuous absence of patient perspectives. In light of their findings, the authors characterised compassion as "arguably one of the most referenced principles of quality care for which there is little empirical evidence." (p. 14). To bridge this gap, two near-term research objectives were

identified: (i) the establishment of a coherent and specific operational definition for compassion, upon which further studies could be based; and (ii) the development of an applied understanding of compassion at the clinical point of delivery.

Having uncovered critical gaps in the literature, Sinclair and colleagues set out to explore compassion from the perspective of care recipients. Convenience and theoretical sampling were used to recruit a sample of 53 patients with advanced cancer in a palliative care setting in Western Canada (2016). Through semi-structured interviews, participants were invited to share their thoughts regarding important contributors to well-being in the context of illness, the meaning and nature of compassion, the feeling and experience of compassion from healthcare providers, the perceived utility of compassion, and the differences between compassion, empathy, and sympathy. Grounded theory analysis of interview transcripts identified seven categories, which are briefly summarized below.

Virtues

The personal character of healthcare providers was identified by participants as prerequisite to the delivery of compassionate care. Compassion was dependent upon the presence of such virtues as love, honestly, sincerity, tolerance, kindness, and care. Healthcare providers whose disposition lacked these qualities were evaluated by patients as incapable of compassion. Attempts to perform compassion by such providers were described by patients as transparent in their half-heartedness and insincerity.

Relational Space

While compassion is predicated on the virtues of the healthcare provider, the experience of compassion requires an interpersonal connection in which those virtues can be perceived and felt by the recipient. It is important to note that the existence of a provider-patient relationship is

not in-itself sufficient for compassionate care. Instead, compassion requires a relationship that transcends provider and patient roles to arrive at the acknowledgement of a shared humanity. It is within this relational space that the act of compassion takes place.

Virtuous Response

This element of compassion entails the activation of healthcare providers' latent virtues in response to patient suffering. Compassionate healthcare providers allow the perspective of the patient to displace their preconceptions, and strive to withstand organizational pressures in order to privilege the needs of patients and the alleviation of suffering.

Seeking to Understand

The delivery of compassionate care requires that healthcare providers move beyond an understanding of disease towards a recognition of and appreciation for the unique person before them. Rather than limiting their practice to the treatment of acute symptoms of pain and suffering, practitioners who embody this aspect of compassion allow their work to be guided by the stated and implied needs of the person who is suffering and tailor their work to fulfil them.

Relational Communicating

Relational communicating encapsulates the verbal and nonverbal expression of compassion through demeanour (for example, body language, gesture, vocal tone), affective empathy, non-clinical relational behaviours (for example, listening, touching, and treating patients with respect), and active commitment to the person in suffering (for example, timely and sensitive communication of information, and tailoring patient interactions to address the specific needs of the patient).

Attending to Needs

The defining element of compassion, which distinguishes it from other forms of care, is action to alleviate the suffering of the other. Within the context of this model, suffering is understood to be multifactorial, with compassionate healthcare providers striving to address the multiple facets of pain, including those that fall outside the scope of clinical practice, such as the emotional, spiritual, and interpersonal. Attending to needs compassionately was described by participants as being both punctual and strategic, with practitioners taking action to address needs *on time*, while also taking into account contextual information to ensure that care is delivered *at the right time*.

Patient-Reported Outcomes

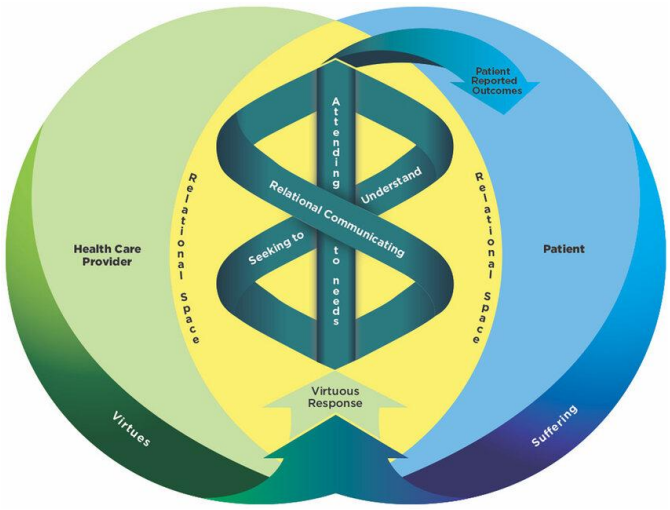
The final element of compassionate care necessarily articulates the effect it has on those who receive it. Compassion was not regarded by participants in the study as a cure for suffering. Instead, compassion was described as an experience that made suffering more bearable, and that also served as a buffer that safeguards patient well-being from the erosive effects of protracted illness.

Consolidation of the themes emerging from the analysis produced a definition of compassion: “a virtuous response that seeks to address the suffering and needs of a person through relational understanding and action” (Sinclair, McClement, et al., 2016, p. 195), as well as a clinical model of compassion, the Patient Compassion Model (Figure 1), both the first of their kind to be empirically-based and patient-informed. A subsequent study exploring compassion from the perspective of healthcare providers generated a congruent (albeit slightly nuanced) model (Figure 2), an unexpected finding that suggests conceptual and perceptual understandings of compassionate care are shared in common by patients and providers alike

(Sinclair, Hack, et al., 2018). In another study, transferability of the Patient Compassion Model was confirmed for patients with life-limiting diagnoses in acute, home, long-term, and hospice care settings (Sinclair, Jaggi, et al., 2018).

Figure 1

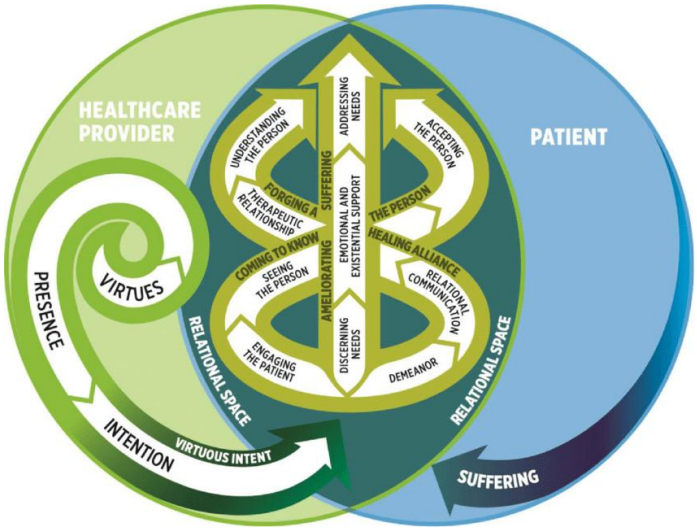
Patient Compassion Model



Note. From "Compassion in Healthcare: An Empirical Model," by S. Sinclair et al., 2016, *Journal of Pain and Symptom Management*, *51(2)*, 193-203. Creative Commons license CC-BY-NC-ND.

Figure 2

Healthcare Provider Compassion Model



Note. From "What are healthcare providers' understandings and experiences of compassion? The healthcare compassion model: a grounded theory study of healthcare providers in Canada," by S. Sinclair et al., 2018, *BMJ Open*, *8*(3), e019701. Creative Commons license CC BY-NC 4.0.

Development of a Valid and Reliable Compassion Measure

The emergence of an empirically-based, patient-informed definition and model of compassion furnished the compassion literature with an answer to a longstanding question: What exactly is compassion? This newfound conceptual clarity laid the blueprint towards resolving

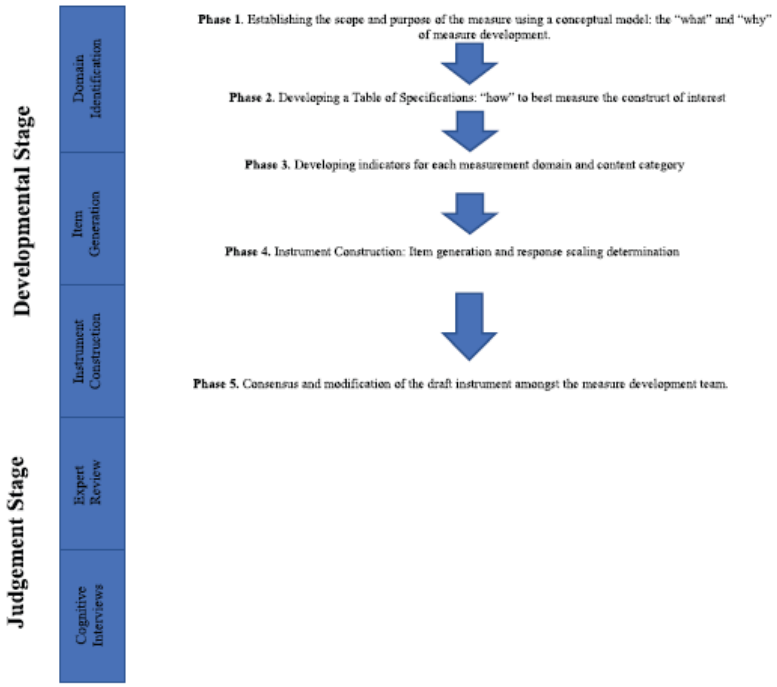
another pressing question: how can compassion be measured? A comprehensive and critical review of the literature (Sinclair, Russell, et al., 2017) identified seven instruments purported to measure compassionate care in clinical settings, but these tools were found to be hampered by significant shortcomings that called into question their validity and reliability. The measures were based upon unempirical conceptualizations of compassion derived from dictionaries, literature searches, or the tool developers themselves, many of which were relics of the terminological conflation that had historically plagued the field. None of the extant measures fully incorporated the qualitative dimensions of compassion identified by patients in earlier research (Sinclair, McClement, et al., 2016). Critically, of the four self-report instruments identified, none possessed the psychometric information necessary to confirm reliability or validity using the standardized "Evaluating the Measurement of Patient-Reported Outcomes" (EMPRO) tool.

Sinclair and colleagues set their empirically-derived definition and model of compassion as the foundation upon which to build a tool that would address the unmet need for a valid, reliable and clinically applicable measure of compassion. Acknowledging the "quantum leap" that item generation entails due to a dearth of practical guidelines or standards, and to overcome the entailed risk to instrument credibility, Sinclair and colleagues followed and thoroughly reported (2020) a five-stage item generation process (Figure 3) that resulted in the creation of an initial pool of 109 thematic and reflective questionnaire items. Content validation was evaluated via a two-round modified Delphi review with an international panel of thirteen Subject Matter Experts and a Patient Advisory Group comprised of twenty patients from the Canadian province of Alberta (Sinclair, Jaggi, Hack, Russell, et al., 2020). The first round of review resulted in the exclusion of 28 questionnaire items, the rephrasing of 10 items, and the addition of 3 new items.

The second round of Delphi review resulted in the further exclusion of 16 items and the rewording of a single item, yielding item-level Content Validity Indices (CVI) of 84% for subject-matter experts and 86% for patient advisors. The content validity of the remaining 68 items was then further assessed through cognitive interviews with a sample of 16 patients with life-limiting diagnoses receiving palliative, home, long-term, or hospice care. Cognitive interviewing resulted in the exclusion of 14 items and the rephrasing of one item, yielding a self-report measure of compassionate care comprised of 54 items of established conceptual relevance and content validity.

Figure 3

Five-phase item generation protocol



Note. From "A practical guide for item generation in measure development: Insights from the development of a patient-reported experience measure of compassion," by S. Sinclair et al., 2020, *Journal of Nursing Measurement*, 28(1), 138–156. Creative Commons license CC BY-NC 4.0. Copyright 1998 by Springer Publishing Company, Inc.

Exploratory factor analysis (EFA) was conducted using a sample of 303 patients recruited from acute, home, long-term, and hospice care settings in two Canadian urban areas (Sinclair, Hack, et al., 2021). Participants completed the 54-item measure. To assess test-retest reliability, the measure was re-administered to a subset of 65 participants within 24 hours of initial exposure to the instrument. In the interest of measurement stability, five items with an intraclass correlation coefficient (ICC) below .70 were removed from the tool. Suitability for factor

analysis was established via the Kaiser-Meyer Olkin measure of sampling adequacy and Bartlett's test of sphericity. Principal axis factor (PAF) extraction with direct oblimin rotation and comparison of factor loadings among similarly worded items resulted in the elimination of a further 11 items. PAF on the remaining 38-item measure supported a single factor model. The fifteen items with the highest factor loadings provided adequate coverage of the domains of compassion identified in the Patient Compassion Model and hence were selected for inclusion in the final iteration of the instrument, the Sinclair Compassion Questionnaire (SCQ). Subsequent administration of the 15-item SCQ on a new sample of 330 participants with life-limiting diagnoses was conducted, alongside the Schwartz Center Compassionate Care Scale (SCCCS), the revised Edmonton Symptom Assessment Scale (ESAS-r), and the PICKER Patient Experience Questionnaire (PPEQ). Support for a single factor of model of compassion was established by Confirmatory Factor Analysis (CFA). As expected, a strong positive correlation ($r = .75$, $p < .001$) was found between scores on the SCQ and SCCCS, confirming convergent content validity between the SCQ and another measure of compassion. Convergent validity of the SCQ was further confirmed vis-à-vis moderate positive correlation with the PPEQ ($r = .60$, $p < .001$), as well as weak and negative correlations with ESAS-r symptom scores of depression ($r = .13$, $p = .02$) and low well-being ($r = -.07$, $p = .002$). Compassion scores were found to be weakly and inversely correlated with age ($r = -.13$, $p = .021$). Analysis of Variance (ANOVA) indicated that SCQ scores differed significantly by service setting ($F(2,327) = 16.62$, $p < .001$), with Tukey post-hoc tests identifying significantly lower scores among patients in long-term care when compared with those among patients in both acute and hospice care. This discrepancy remained even after controlling for age ($F(3,316) = 11.65$, $p < .001$).

On the heels of the creation of the 15-item SCQ, a follow-up review of available compassion measures was conducted (Sinclair et al., 2022). The review used the EMPRO tool to evaluate the psychometric properties of nine measures: three instruments that had undergone amendments since the previous review (Sinclair, Russell, et al., 2017), three new instruments, and the Sinclair Compassion Questionnaire. By a wide margin, the SCQ obtained a higher score than any other tool and was found to be the sole instrument to satisfy EMPRO criteria for validity and reliability, thus establishing the Sinclair Compassion Questionnaire as the "gold standard" empirical measure of compassion in healthcare settings.

Compassion in Long-Term Care

The Patient Compassion Model and the Sinclair Compassion Questionnaire serve as the foundation for an empirical understanding and calibration of compassionate care. These critical contributions have opened to door to multiple avenues of compassion research: family experiences in pediatric oncological care (Sinclair, Bouchal, et al., 2021; Sinclair, Jaggi, et al., 2022; Sinclair, Kondejewski, et al., 2020), patient experiences in urgent care (Boss et al., 2024) and psychiatry (Bond et al., 2024), healthcare provider experiences (Pavlova et al., 2023), compassion training (Sinclair et al., 2023, 2024; Sinclair, Hack, McClement, Raffin-Bouchal, et al., 2020; Sinclair, Kondejewski, Jaggi, Dennett, et al., 2021; Sinclair, Kondejewski, Jaggi, Roze des Ordons, et al., 2021; Sinclair, Torres, et al., 2016), and compassionate care experiences among diverse ethnic and linguistic communities (Bovero et al., 2024; Chu et al., 2023; Soto-Rubio et al., 2024). The presence of long-term care perspectives in this literature is scarce (Smith-MacDonald et al., 2019), a conspicuous absence when considering the unprecedented and ongoing demographic shift underway in many developed countries, including Canada, where nearly one in five individuals is aged 65 or older, and where the number of citizens aged 85 and

older is one of the most rapidly-growing age segments (Government of Canada, 2019, 2022). By virtue of the prevalence of chronic disease (Canada, 2021), cognitive impairment (*This Is Long-Term Care 2018*, 2018), and loss of independence (Hakimjavadi et al., 2025), the long-term care setting has, moreover, been conceptualized as a site of special proximity to suffering, where compassion may play a particularly relevant role in the alleviation of spiritual and psychological distress (Sinclair, Norris, et al., 2016). Thematic analysis of transcripts from focus groups of long-term care residents, providers, and care partners found that the conceptualization of compassionate care in this population is congruent with models of patient and provider compassion that had emerged in previous studies (Smith-MacDonald et al., 2019). The authors of that study noted, importantly, that facets of the compassion construct concerning relational understanding and communication were regarded with heightened importance in the long-term care context, where functional and cognitive impairment, among other factors, may prevent healthcare providers from perceiving residents as persons, a phenomenon that has been associated with lower quality of life (Eritz et al., 2016). The heightened value placed upon relational aspects of compassion merits attention, given recent research suggesting that long-term care is one of the least compassionate care settings frequented by older adults (Sinclair, Hack, et al., 2021). Furthermore, earlier findings that female recipients of urgent care may receive lower levels of compassion than male counterparts (Boss et al., 2024), forecasts a potential gender-based discrepancy in long-term care, where 65% of residents identify as female (Government of Canada, 2021).

Care-Partners: A Vital and Understudied Perspective

The Sinclair Compassion Questionnaire furnishes researchers with a tool that can begin to illuminate the nature and impact of compassion in long-term care, but its utility is constrained

by its reliance on patient report, a shortcoming that impairs compassionate care research in settings where patients lack the capacity to interpret or evaluate the nature of the care they receive, or to engage with a standardized measurement protocol. This poses a particular setback to compassionate care research in long-term care settings, where over 90% of residents live with some form of cognitive impairment (*This Is Long-Term Care 2018*, 2018). In such circumstances, care-partners (family members, substitute decision makers, loved ones who are closely and regularly involved in the patient's healthcare experience) constitute a vital source of insight and information. Unfortunately, no tool is currently available to measure this construct from that perspective. The study here proposed aims to address this gap by adapting and validating a new version of the Sinclair Compassion Questionnaire (SCQ-CP) which has been semantically adapted to measure compassionate care from the perspective of care-partners.

Methods

The research team carried out a semantic modification of the original Sinclair Compassion Questionnaire with an aim to tailor it for proxy use with care-partners. The semantic modification process adjusted the narrative perspective of the original items, such that they shifted from first- to third-person, thereby grammatically enlisting the point-of-view of the care-partner. Differences of opinion that emerged between members of the research team were resolved through discussion, with the author of the original SCQ providing final approval for the text of the adapted version.

Study Sample and Data Collection

Phase 1: Pre-testing of the SCQ-CP

A sample of care-partners were recruited from two long-term care residences in a large urban centre in Northwestern Ontario, Canada. Criteria for eligibility were as follows: the care-

partner must provide at least weekly care for a resident at one of the two study sites, be able to speak, read, and write in English, and be 18 years of age or older. In consideration of the emotional complexity that accompanies the care-giving experience, especially during and after the transition to long-term care, recruitment was facilitated by residential staff, who provided a brief, verbal description of the study to care-partners who they believed may be both eligible for and interested in participation. With their initial consent, the names and contact information of potential recruits were forwarded by residential staff to the study team. The study team reached out to potential recruits in random order to confirm continued interest in the study and arrange for an in-person meeting.

In-person meetings took place in a private meeting room located within one of the long-term care residences or another organizationally-affiliated site, as determined by participant preference. A thorough description of the study along with all details relevant to the informed decision to participate was followed by an opportunity for potential recruits to pose questions and raise any concerns. After questions and concerns were addressed to the satisfaction of the potential recruit and informed consent was established, data collection began in the form of a voice-recorded, semi-structured cognitive interview. The aim of the interview was to qualitatively assess how care partners interpret and respond to the SCQ-CP. As outlined in Collins' pretesting framework for survey instruments (2003), the cognitive interview consisted of (i) a think-aloud approach, in which participants were invited to read aloud each survey item and to narrate the cognitive process of understanding and responding to them; and (ii) a probing approach, in which a member of the research team posed specific questions to clarify initial responses, elicit additional detail, and verify item comprehension, acceptability, and difficulty.

Participants in this phase received a $25.00 gift card in recognition of their contribution to the study.

Phase 2a: Validation of the SCQ-CP

A sample of care-partner/resident dyads was recruited at the same facilities engaged in Phase 1. Eligible dyads were comprised of a care-partner who: provides at least weekly care for a resident at one of the two study sites, can speak, read, and write in English, is 18 years of age or older, and did not participate in Phase 1 of the study; and a resident who: is cognitively intact as measured by a cognitive performance scale (CPS) score less than or equal to 1, and can speak, read, and write in English. Two strategies were deployed to recruit participants: direct approach by residential staff, or indirect approach via a temporary information booth manned by the principal researcher in a high-traffic location within the facility site. Potential participants received a brief oral description of the study. Those parties who confirmed interest in participation and consented to further correspondence from the study team were subsequently contacted to schedule two separate in-person meetings, one for each half of the dyad.

All meetings were conducted in-person. Meetings with residents took place in their respective accommodations. Most care-partner meetings were held in private office spaces within the long-term care facility or another organizationally-affiliated site, as determined by participant preference. Two meetings were held at a private dwelling, at the request of a care-partner, in order to accommodate restricted physical mobility. A thorough description of the study along with all details relevant to the informed decision to participate was followed by an opportunity for potential recruits to pose questions and raise any concerns. After questions and concerns were addressed to the satisfaction of the potential recruit and informed consent was established, data collection began. To residents, the original Sinclair Compassion Questionnaire

was administered (see Appendix A). To care-partners, the adapted Sinclair Compassion Questionnaire (see Appendix B) was administered, as well as a minimally-revised Canadian Health Care Evaluation Project (CANHELP Lite) Long-Term Care Questionnaire (Nadin et al., 2017) (see Appendix C). The CANHELP Lite is a caregiver-reported, 21-item survey that assesses family satisfaction with end-of-life care. Validation of the measure was established using a sample of 193 family members. Internal consistency using Cronbach's alpha was found to range from questionable to excellent (.69 to .93), and moderate to strong correlations with measures of care satisfaction and quality of life support its construct validity (Heyland et al., 2013). For the present study, the CANHELP Lite was semantically adapted to enhance care-partner applicability, and 3 items unrelated to the long-term care experience were omitted.

With an aim to obtain a sample size that approaches the power needed to analyse convergent validity ($N = 54$, based on a Pearson correlation of .6, CI 95% [.40-.75]) single care-partners were recruited in addition to those care-partners included in the dyads described above. Eligibility criteria, as well as recruitment and data collection protocols for these participants was identical to those described in the preceding paragraph. Participants in this phase received a gift card in the amount of $20.00 in recognition of their contribution to the study.

Phase 2b: Reproducibility of the SCQ-CP

Care-partners who participated in Phase 2a were invited to participate in a second administration of the SCQ-CP. This follow-up administration took place approximately 30 days after the administration of Phase 2a, at a date, time, and location that was convenient to the participant. Participation of a minimum of 40 care-partners was targeted to ensure adequate sample size for test-retest reliability analysis (based on an ICC of .7, CI 95% [0.50 0.83]).

Participants in this phase received a gift card in the amount of $20.00 in recognition of their contribution to the study.

Data Analysis

Phase 1: Development and pre-testing of the SCQ-CP

Initial analysis of qualitative data generated from the semi-structured cognitive interviews was conducted by a member of the research team. An iterative analytical process was followed, whereby each participant response to each item was compared with those of previous participants. Participant feedback, response patterns, themes, and outliers emerging from this analysis were summarized by the researcher and subsequently shared with the larger research team. Based on this analysis, potential revisions to the SCQ-CP were discussed by the research team, with differences of opinion resolved by consensus and final approval from the author of the original tool.

Phase 2a: Validation of the SCQ-CP

Internal consistency of the SCQ-CP was evaluated using item-total correlations to explore the associations between item-level and total scores, as well as by using Cronbach's alpha. It was anticipated that these analyses would suggest good internal consistency by way of strong, positive associations between items and Cronbach's alpha ($\geq .7$). Convergent validity was assessed using Pearson's correlation to determine the strength and direction of the relationship between total scores on the SCQ-CP and the CANHELP Lite. Congruence between care-partner and resident perspectives was assessed using Pearson's correlation to determine the strength and direction of the relationships between care-partner and resident responses to their respective tools. In Pearson's correlation, the strength of a relationship is denoted by its absolute value, where 0 indicates the absence of a linear relationship, and 1 indicates the presence of a perfect linear relationship. The direction of the relationship is determined by the positivity or negativity

of the correlation, where positivity denotes a direct correlation, and negativity denotes an inverse correlation. A moderate, positive, but imperfect correlation ($r \geq 0.5$) was expected to emerge both between SCQ-CP and CANHELP Lite scores, and between respective care-partner and resident ratings of compassion using the SCQ-CP and SCQ. Additionally, a two-way mixed-effects Intraclass Correlation Coefficient model was used to evaluate absolute agreement between care-partner and resident ratings of compassionate care. The absence of reliability is denoted by an ICC of 0, whereas perfect reliability is denoted by an ICC of 1. To corroborate reproducibility, a target ICC was set at .7.

Phase 2b: Reproducibility of the SCQ-CP

Test-retest reliability was assessed using a two-way mixed-effects Intraclass Correlation Coefficient model to evaluate the consistency of intra-rater responses across repeated administrations. As above, a target ICC was set at .7.

Results

Phase 1

Participant Characteristics

A sample of 11 care-partners was recruited. As shown in Table 1, participants ranged in age from 40 to 85 years ($M = 66.09$, $SD = 11.30$). Ten participants (90.9%) identified as female, with the remaining participant (9.1%) identifying as male. The majority of participants in this sample reported visiting a loved-one in long-term care for between 1 and 5 years ($n = 7$, 63.6%), with the remaining participants reporting visiting on a weekly basis for between 1 and 6 months ($n = 2$, 18.2%) and between 6 and 10 years ($n = 2$, 18.2%). Most members of the sample described their loved-one in long-term care as spouse/partner ($n = 5$, 45.5%) or parent ($n = 5$, 45.5%), with a single participant reporting an in-law relationship (9.1%).

Table 1

Sociodemographic Characteristics of Phase 1 Participants

Baseline characteristic	Full sample	
	n	%
Gender		
Female	10	90.9
Male	1	9.1
Duration Weekly Visits		
1-6 months	2	18.2
1-5 years	7	63.6
6-10 years	2	18.2
Relationship to Resident		
Spouse/Partner	5	45.5
Child	5	45.5
In-Law	1	9.1

Note. $N = 11$. Participants were on average 66.09 years old ($SD = 11.30$).

Pre-Testing of the SCQ-CP

Phase 1 sessions varied in duration, ranging from approximately 30 minutes to 3 hours. Participant reactions and responses emerging from both "think-aloud" and "probing" methods indicated that the text of the SCQ-CP is comprehensible, and that the meaning of the text is interpreted uniformly. Participants also endorsed SCQ-CP items as acceptable and easy to answer. Recurrent feedback from participants focalized three sources of potential misunderstanding for prospective users of the SCQ-CP:

Meaning of the term "Healthcare Providers". Participant responses to questionnaire items were routinely punctuated by hesitation surrounding the term "Healthcare Providers".

Care-partners expressed that the interdisciplinary nature of long-term care made it difficult to intuit which disciplines or staff members to include in their assessment, and which to exclude. This feedback resulted in the amendment of the SCQ-CP preamble to provide an explicit definition for the term, as illustrated in Figure 4.

Figure 4

Amendment of SCQ-CP preamble to explicitly define "Healthcare Provider"

Preamble (original)		Preamble (amended)
This questionnaire was developed to ask you about you experience with the following aspects of compassionate care. Please carefully read each question and rate your level of agreement with it.		This questionnaire was developed to ask you about you experience with the following aspects of compassionate care *involving healthcare providers. By healthcare providers, we mean all staff who interacted directly with the resident (for example, nurses, personal support workers, housekeepers).* Please carefully read each question and rate your level of agreement with it.

Balancing multiple experiences. Citing the interdisciplinary nature of long-term care and the quantity and range of healthcare provider interactions that take place in the course of a 7-

day period, participants expressed that there were a number of ways to formulate their responses and sought to clarify which method they were meant to use for the purposes of the adapted tool. This feedback resulted in the amendment of the SCQ-CP guiding instructions to specify that item ratings should represent an overall impression of their full collection of observations, rather than a single observation or select grouping thereof, as illustrated in Figure 5.

Figure 5

Amendment of SCQ-CP instructions to specify rating of overall impression

Instructions (original)		Instructions (amended)
In thinking about the resident's Healthcare Providers over the past 7 days, please rate the following:	→	*Overall,* in thinking about the resident's Healthcare Providers over the past 7 days, please rate the following:

Emphasis on patienthood rather than residential status. A pattern of objection emerged in relation to the wording of Item 9, which asked care-partners to rate the extent to which healthcare providers moved beyond generic impressions to recognize the unique personhood of their loved ones. Participants routinely voiced their objection to the item's use of the terms "resident" and "person" to express these contrasting relational approaches. Participants communicated that while they understood the item's intended meaning, the semantic distance between "resident" and "person" was not sufficiently wide to capture its spirit. Participants agreed that using the term "patient" in place of "resident" offered a more suitable illustration of the reductionist-holistic dichotomy. As such, the item was amended to reflect that preference, as illustrated in Figure 6.

Figure 6

Amendment of SCQ-CP Item 9

Item 9 (original)		Item 9 (amended)
The Healthcare Providers saw the resident as a person, and not just as a resident.		The Healthcare Providers saw the resident as a person, and not just as a *patient*.

Phases 2a and 2b

Participant Characteristics

Resident/Care-Partner Dyads. A sample of 15 resident/care-partner dyads was recruited. As shown in Table 2, resident participants ranged in age from 61 to 95 years (M = 80.40, SD = 11.15). Ten resident participants (66.66%) identified as female, with the remaining five residents (33.33%) identifying as male. The majority of resident participants reported living in their long-term care residence for between 1 and 5 years (n = 9, 60%), with the remaining residents reporting residency for between 1 and 6 months (n = 2, 13.3%) and between 7 and 11 months (n = 4, 26.7%). Dyadic care-partners ranged in age from 45 to 78 years (M = 61.47, SD = 8.535), with 9 (60.0%) identifying as female, and 6 (40.0%) identifying as male. The majority of dyadic care-partners endorsed visiting their loved-one on a weekly basis for between 1 and 5 years (n = 8, 53.3%), with remaining dyadic care-partners reporting visiting on a weekly basis for between 1 and 6 months (n = 3, 20.0%), between 7 and 11 months (n = 3, 20.0%), and between 6 and 10 years (n = 1, 6.7%). Most dyadic care-partners described their loved-one in long-term care as a parent (n = 8, 53.3%), with the remainder reporting spouse/partner (n = 3, 20.0%), sibling (n = 2, 13.3%) or friend (n = 2, 13.3%) relationships.

Table 2

Sociodemographic Characteristics of Phase 2 Resident/Care-Partner Dyad Participants

Baseline characteristic	Residents		Care-Partners	
	n	%	*n*	%
Gender				
Female	10	66.7	9	60.0
Male	5	33.3	6	40.0
Duration of Residence				
1-6 months	2	13.3	-	-
7-11 months	4	26.7	-	-
1-5 years	9	60	-	-
Duration Weekly Visits				
1-6 months	-	-	3	20.0
7-11 months	-	-	3	20
1-5 years	-	-	8	53.3
6-10 years	-	-	1	6.7
Relationship to Resident				
Spouse/Partner	-	-	3	20.0
Child	-	-	8	53.3
Sibling	-	-	2	13.3
Friend	-	-	2	13.3

Note. $N = 15$ ($n = 15$ for Residents and Care-Partners respectively). Residents were on average 80.4 years old ($SD = 11.2$), and Care-Partners were on average 61.5 years old ($SD = 8.5$).

Single Care-Partners. A further 29 care-partners were recruited with an aim to increase the power of subsequent convergent validity and reliability analyses. As illustrated in Table 3, these participants ranged in age from 49 to 85 years ($M = 68.66$, $SD = 8.949$). Of them, twenty-two (75.9%) identified as female, with the remaining seven (24.1%) identifying as male. The majority of participants in this sample reported visiting a loved-one in long-term care for between 1 and 5 years ($n = 26$, 89.7%), with the remaining participants reporting visiting on a weekly basis for between 7 and 11 months ($n = 1$, 3.4%), between 1 and 6 months ($n = 1$, 3.4%), and less than one month ($n = 1$, 3.4%). Most described their loved-one in long-term care as a parent ($n = 12$, 41.4%) or spouse/partner ($n = 9$, 31.0%), with a minority of participants reporting

a sibling (*n* = 3, 10.3%), in-law (*n* = 1, 3.4%), friend (*n* = 1, 3.4%), or child (*n* = 1, 3.4%) relationship. Due to a technical oversight, resident/care-partner relationship was not recorded for two care-partners (6.9%).

Table 3

Sociodemographic Characteristics of Phase 2 Single Care-Partner Participants

Baseline characteristic	Single Care-Partners	
	n	%
Gender		
Female	22	75.9
Male	7	24.1
Duration Weekly Visits		
< 6 months	1	3.4
1-6 months	1	3.4
7-11 months	1	3.4
1-5 years	26	89.7
Relationship to Resident		
Spouse/Partner	9	31.0
Child	12	41.4
Sibling	3	10.3
In-Law	1	3.4
Friend	1	3.4
Parent	1	3.4
Not recorded	2	6.9

Note. $N = 29$. Participants were on average 68.7 years old ($SD = 9.0$).

Amalgamated Care-Partner Sample. The full sample of care-partners comprised 44 participants. Care-partners ranged in age from 45 to 85 years ($M = 66.2$, $SD = 9.37$). As illustrated in Table 4, 31 care-partners (70.5%) identified as female, with the remaining 13

(29.5%) identifying as male. The majority of care-partners reported visiting a loved-one in long-term care on a weekly basis for between 1 and 5 years (*n* = 34, 77.3%), with the remaining participants reporting visiting on a weekly basis for between 6 and 10 years (*n* = 1, 2.3%), between 7 and 11 months (*n* = 4, 9.1%), between 1 and 6 months (*n* = 4, 9.1%), and less than 1 month (*n* = 1, 2.3%). Nearly three-quarters of care-partners described their loved-one in long-term care as either a parent (*n* = 20, 45.5%) or spouse/partner (*n* = 12, 27.3%), with the remainder reporting a sibling (*n* = 5, 11.4%), friend (*n* = 3, 6.8%), in-law (*n* = 1, 2.3%), or child (*n* = 1, 2.3%) relationship. Due to a technical oversight, resident/care-partner relationship was not recorded for two care-partners (4.5%).

Table 4

Sociodemographic Characteristics of Amalgamated Phase 2 Care-Partner Participants

Baseline characteristic	Care-Partners	
	n	%
Gender		
Female	31	70.5
Male	13	29.5
Duration Weekly Visits		
< 6 months	1	2.3
1-6 months	4	9.1
7-11 months	4	9.1
1-5 years	34	77.3
6-10 years	1	2.3
Relationship to Resident		
Spouse/Partner	12	27.3
Child	20	45.5
Sibling	5	11.4
In-Law	1	2.3

Friend	3	6.8
Parent	1	2.3
Not recorded	2	6.9

Note. $N = 44$. Participants were on average 66.2 years old ($SD = 9.4$).

Descriptive Statistics

The duration of Phase 2a sessions varied, with resident sessions ranging from approximately 45 to 90 minutes, and care-partner sessions ranging from approximately 30 to 60 minutes. As shown in Table 5, within the dyadic sample, resident SCQ scores ranged from 56 to 74 points ($M = 65.53$, $SD = 5.10$), and care-partner scores on the first administration of the SCQ-CP ranged from 36 to 75 points ($M = 64.80$, $SD = 10.36$). On either measure, the highest possible score amounted to 75 points.

Table 5

Range, means, and standard deviations for Resident SCQ scores and Care-Partner SCQ-CP scores (first administration).

Measure	Residents					Care-Partners				
	n	Min	Max	*M*	*SD*	*n*	Min	Max	*M*	*SD*
SCQ	15	56	74	65.53	5.10	-	-	-	-	-
SCQ-CP (time 1)	-	-	-	-		15	36	75	64.80	10.36

Note. The maximum score possible, on either measure, is 75.

Collapsing all care-partners into a single amalgamated group, and taking into account a small number of missing entries, prorated care-partner scores ranged from 30 to 75 points ($M = 64.32$, $SD = 10.54$) on the first administration of the SCQ-CP. On the CANHELP Lite, scaled scores ranged from 8.33 to 100 points ($M = 76.78$, $SD = 20.35$), with a score of 100 being the highest possible.

The duration of Phase 2b sessions varied, ranging from approximately 15 to 30 minutes. Nine care-partners were lost to follow-up; as such, 35 care-partners completed Phase 2b. Collapsing all care-partners into a single amalgamated group, and taking into account a small number of missing entries, prorated care-partner scores ranged from 38 to 75 points (M = 64.80, SD = 9.46) on the second administration of the SCQ-CP. These descriptive statistics are summarized in Table 6.

Table 6

Range, means, and standard deviations for CANHELP Lite, Care-Partner SCQ-CP (time 1), and SCQ-CP (time 2) scores.

Measure	Care-Partners				
	n	Min	Max	*M*	*SD*
CANHELP Lite	44	8.33	100.00	76.78	20.35
SCQ-CP (time 1)	44	30.00	75.00	64.32	10.54
SCQ-CP (time 2)	35	38.00	75.00	64.80	9.46

Note. The maximum score possible is 100 on the CANHELP Lite, and is 75 on the SCQ-CP.

Validation of the SCQ-CP

Internal Consistency. The first and second administrations of the SCQ-CP both yielded a Cronbach's alpha of .97, indicating a high-degree of internal consistency that is appropriate for a unidimensional measurement tool. Inter-item correlations were calculated, ranging between .49 and .84 on the first administrations (see Table 7), and between .39 and .87 on the second (see Table 8). Corrected item-total correlations were calculated, ranging between .74 and .89 on the first administration (see Table 9), and between .68 and .90 on the second (see Table 10). Highly correlated items, such as those described here, lend further credibility to the internal consistency of the SCQ-CP by indicating that individual survey items are measuring a single underlying construct.

Table 7

Inter-item correlations for SCQ-CP (time 1)

Item	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1	—														
2	.696	—													
3	.702	.842	—												
4	.689	.700	.732	—											
5	.721	.725	.664	.704	—										
6	.650	.708	.833	.820	.595	—									
7	.670	.632	.654	.766	.600	.764	—								
8	.599	.691	.655	.644	.555	.816	.736	—							
9	.620	.711	.676	.723	.609	.708	.706	.616	—						
10	.797	.809	.773	.722	.819	.691	.645	.595	.768	—					
11	.756	.806	.822	.729	.683	.724	.748	.624	.759	.782	—				
12	.652	.692	.710	.795	.622	.827	.783	.619	.732	.708	.748	—			
13	.586	.711	.675	.700	.558	.614	.690	.656	.659	.657	.790	.584	—		
14	.753	.751	.770	.578	.712	.630	.575	.658	.632	.768	.750	.637	.605	—	
15	.766	.740	.743	.628	.683	.520	.619	.523	.663	.760	.751	.490	631.	.738	—

Table 8

Inter-item correlations for SCQ-CP (time 2)

Item	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1	—														
2	.826	—													
3	.665	.704	—												
4	.640	.561	.556	—											
5	.783	.712	.706	.717	—										
6	.731	.700	.846	.552	.719	—									
7	.706	.593	.734	.656	.801	.723	—								
8	.774	.807	.778	.466	.714	.771	.696	—							
9	.791	.767	.771	.613	.706	.734	.666	.719	—						
10	.756	.722	.641	.561	.762	.639	.742	.742	.830	—					
11	.639	.541	.652	.629	.811	.656	.749	.601	.698	.742	—				
12	.665	.628	.759	.401	.713	.754	.720	.869	.690	.703	.637	—			
13	.715	.583	.574	.701	.693	.598	.588	.546	.701	.676	.775	.528	—		
14	.791	.704	.599	.385	.660	.623	.598	.837	.713	.704	.607	.827	.532	—	
15	.834	.815	.743	.533	.718	.772	.671	.818	.848	.757	.674	.816	.743	.848	—

Table 9

Item-total statistics for SCQ-CP (time 1)

Item	Corrected Item-total Correlation	Cronbach's Alpha if Item Deleted
1	.813	.967
2	.867	.966
3	.870	.966
4	.843	.967
5	.775	.968
6	.835	.967
7	.811	.967

8	.739	.969
9	.810	.967
10	.873	.966
11	.893	.966
12	.812	.967
13	.764	.969
14	.798	.967
15	.780	.968

Table 10

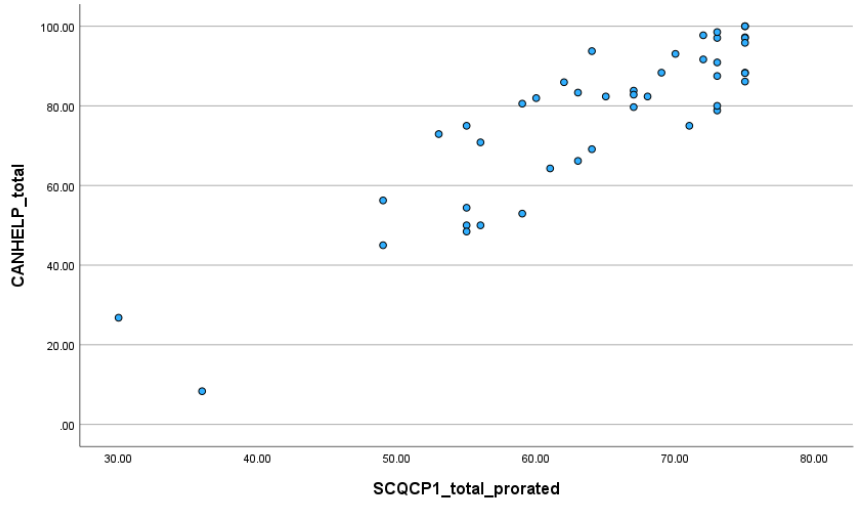
Item-total statistics for SCQ-CP (time 2)

Item	Corrected Item-total Correlation	Cronbach's Alpha if Item Deleted
1	.874	.966
2	.811	.967
3	.817	.967
4	.675	.969
5	.866	.966
6	.826	.967
7	.815	.967
8	.848	.96
9	.868	.966
10	.844	.967
11	.800	.968
12	.815	.967
13	.758	.969
14	.787	.967
15	.897	.965

Convergent Validity. Cronbach's alpha for CANHELP Lite scores is not reported here. This decision was made in view of the tool's response scale, which provides a "Don't Know/No Basis To Judge" option which, rather than indicating a degree of satisfaction, represents the absence of experience needed to engage with the item in a meaningful way. The selection of this option by respondents effectively results in the exclusion of individual items from the overall score, a state of affairs that cannot be accommodated by Cronbach's alpha, which assumes that individual items contribute to the total. It was determined that Cronbach's alpha would not render a reliable estimate of internal consistency and as such, the CANHELP Lite was not formally assessed for this property. The SCQ-CP and CANHELP Lite were strongly and positively correlated, $r(42) = .89$, 95% CI [.81, .94], $p < .001$. A visual rendering of this relationship is provided in Figure 7.

Figure 7

Relationship between SCQ-CP and CANHELP Lite scores

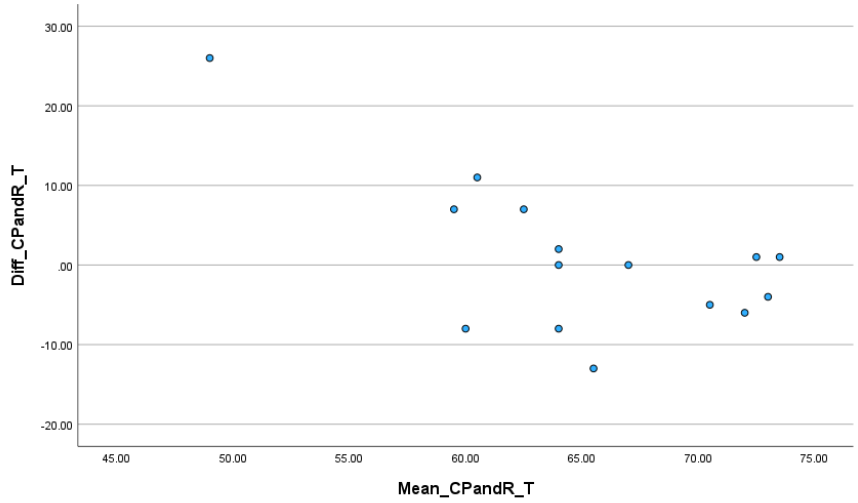


Resident/Care-Partner Congruence A positive trend was found between resident and care-partner ratings of compassionate care, although this relationship was not statistically significant, $r(13) = .41$, 95% CI [-.09, .84], $p = .134$. Visual inspection of this association identified the presence of a resident/care-partner dyad with atypically discrepant scores. A sensitivity analysis was conducted to assess the potential impact of this dyad on overall dyadic association, which found it to be of minimal influence, $r(12) = .41$, 95% CI [-.17, .82], $p = .144$.

Resident/Care-Partner Agreement. Two-way mixed-effects Intraclass Correlation Coefficient analysis found trending towards poor absolute agreement between resident and care-partner scores, ICC(3,1) = .34, 95% CI [-.23, .72], $p = .113$. Inspection of the Bland-Altman difference plot (see Figure 8), which serves as a visual representation of agreement between two measurements, indicates that most resident/care-partner dyad total scores were within 10 points of each other. Within the context of a 15-item questionnaire with a 5-scale response format, a 10-point difference in total score amounts to item-level response differences of less than one point. Visual inspection also identified the presence of a resident/care-partner dyad with atypically discrepant scores. A sensitivity analysis was conducted to assess the potential impact of this dyad on overall agreement. Sensitivity analysis findings indicated that exclusion of the extreme dyad strengthened the inter-rater agreement point estimate, while remaining statistically non-significant ICC(3,1) = .41, 95% CI [-.15, .76], $p = .072$.

Figure 8

Agreement between Resident and Care-Partner ratings of compassionate care



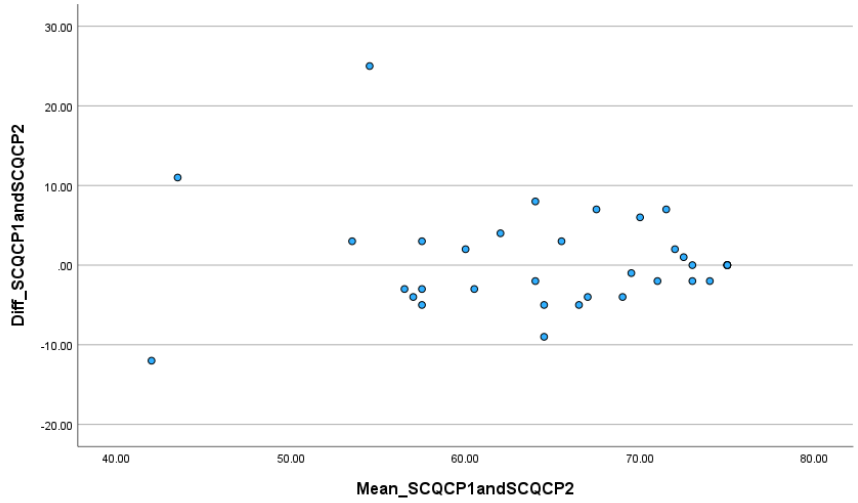
Note. In the case of perfect agreement, $Y = 0$.

Reproducibility of the SCQ-CP

Test-Retest Reliability. Two-way mixed-effects Intraclass Correlation Coefficient analysis found excellent test-retest reliability, ICC(3,1) = .767, 95% CI [.585, .875], $p < .001$. Inspection of the Bland-Altman difference plot (see Figure 9), which serves as a visual representation of agreement between two measurements, indicates that for most care-partners, time 1 and time 2 total scores were within 10 points of each other. Within the context of a 15-item questionnaire with a 5-scale response format, a 10-point difference in total score amounts to item-level response differences of less than one point.

Figure 9

Agreement between SCP-CP (Time 1) and SCQ-CP (Time 2) Total Scores



Exploratory subgroup analysis found that the strength and certainty of absolute agreement across tool administrations were similar across genders, with roughly similar test-retest reliability among female care-partners, ICC(3,1) = .776, 95% CI [.547, .897], $p < .001$, and male care-partners, ICC(3,1) = .712, 95% CI [.213, .914], $p = .006$.

Discussion

Summary of Findings

This study verifies the comprehensibility, acceptability, and ease-of use of a measure of compassionate care that was adapted for use by informal care-partners. Findings of excellent internal consistency, strong convergent validity with an established measure of healthcare satisfaction in long-term care, and excellent test-retest reliability provide preliminary evidence of the SCQ-CP's psychometric validity and reliability. Statistically inconclusive trending towards a positive but inexact relationship between care-partner and resident ratings of compassionate care

suggest that the SCQ-CP may serve as an informative but imperfect proxy in long-term care settings where the administration of the SCQ is precluded.

Interpretation

The credibility and utility of measurement tools, rather than static labels, are dynamic determinations made by researchers and clinicians who use professional judgement to balance an ever-evolving body of evidence. Close attention is paid to measures of validity and reliability, and quite rightly, as a tool that fails to measure what it claims to measure, and/or fails to measure it consistently, is no tool at all. While essential components of an instrument's appraisal, in the case of questionnaires such as the SCQ-CP, validity and reliability are contingent upon the ability of respondents to understand the text of the instrument, capture its intended meaning, access the information needed to formulate a pertinent response, and encapsulate that response in a way that corresponds to questionnaire format (Collins, 2003). These assumptions are sometimes overlooked or taken for granted by tool users and tool developers alike.

Results from the pre-testing phase of this study provide evidence of the suitability of the SCQ-CP for its target population. Prospective users of this measure can be confident that informal care-partners in long-term care settings interact with the SCQ-CP in a way that is consistent with the tool's intended design, and that care-partner responses are reflective of the compassion construct that the tool is meant to represent. Care-partner endorsement of the acceptability of the SCQ-CP aligns harmoniously with qualitative research that found that care-partner perceptions of compassion in long-term care correspond closely with the Patient Compassion Model upon which the SCQ-CP items are based (Smith-MacDonald et al., 2019). Importantly, these findings also validate ease-of-use, providing assurance that use of the tool should not constitute a burden for members of a population that experiences high levels of

emotional and cognitive stress (Brodaty et al., 2014). In these ways, findings from this study validate the fundamental cognitive assumptions upon which psychometric evaluations of validity and reliability depend (Collins, 2003), and thereby contribute an important layer of credibility to the statistical analyses discussed below.

Internal consistency refers to the extent to which individual questionnaire items measure the same underlying construct. This property is an important consideration in the determination of a tool's utility and credibility, as poor internal consistency is indicative of an instrument comprised of items that are only loosely related to one another and to overall scores (Streiner, 2003). Findings from this study were consistent with those anticipated, showing excellent levels of association between items as well as between individual items and total scores. These results support the SCQ-CP's claim to measure a single construct. It is important to note, however, that while some degree of internal consistency is desirable, the level achieved by this SCQ-CP may be indicative of item redundancy (Tavakol & Dennick, 2011). That is to say, rather than capturing discrete facets of a single construct as intended, highly correlated items may simply employ different phrasing to repeat a single question. Notwithstanding concerns of potential item overlap, the present findings are nearly identical to those reported for the original SCQ (Sinclair, Hack, et al., 2021) and therefore lend support to its intended use as an equivalent measure of compassionate care.

Convergent validity refers to the strength of association between two measures of theoretically related constructs. A finding of strong correspondence between scores on a novel tool and scores on an established tool that measures a similar concept provides assurance that the new tool is, in fact, measuring what it claims to measure. A finding of poor correspondence, conversely, casts doubt on an instrument's ability to capture its target construct (Strauss & Smith,

2009). The present study found, as expected, that SCQ-CP scores are positively linked with CANHELP Lite scores. Respondents who provided low ratings of compassionate care tended to provide low ratings of overall healthcare satisfaction, and vice-versa. Similarly to internal consistency, findings of strong convergent validity are accompanied by an important pitfall: extreme overlap on related measures raises the concern that a measure may lack the specificity needed to discriminate between similar constructs. Taking into consideration a previous study on the original SCQ, which identified patient ratings of compassionate care as the single strongest associate of overall healthcare satisfaction ratings (Boss et al., 2024), the strong correspondence identified by this study can be rationalized as evidence to support the equivalence of the SCQ-CP with the original SCQ, and as an attestation to the existing literature which links care-partner perception of compassion to their appraisals over healthcare quality (Attree, 2001; Garrett et al., 2008; Riggs et al., 2014).

Taken together, the findings of strong internal consistency and convergent validity provide robust assurance that the SCQ-CP successfully captures the construct of compassionate care in long-term care settings.

Inter-rater congruence refers to the strength of association between the responses of different parties reporting on the same phenomenon (Goodwin, 2001; Tinsley & Weiss, 1975). In the present study, this metric serves as an indication of the degree to which the ratings of care-partners covary with those of their loved ones in long-term care. It may be helpful to liken this statistical concept to the musical property of harmony, which entails the playing of notes that are different, but complementary. Positive trending was weaker than anticipated a priori and provides a tentative indication that care-partner and resident ratings of compassionate care tend to vary in imperfect harmony. Such an interpretation must be treated with extreme caution,

however, as a wide confidence interval, which includes the value of zero, indicates that the present sample lacked sufficient power to detect any true effect. Notwithstanding the above limitations, these findings suggest that SCQ-CP scores may provide a reasonable reflection of resident general impressions of compassionate care.

Inter-rater agreement refers to the extent to which ratings of different parties reporting on the same phenomenon match exactly (Goodwin, 2001; Tinsley & Weiss, 1975). If congruence can be likened to harmony, then agreement is akin to unison, which occurs when multiple musicians play a common note. Agreement provides an additional layer of specificity to the understanding of inter-rater consistency, as it is sensitive to the presence of systematic bias, which correlational analyses cannot detect (Bédard et al., 2000). Analysis of the full sample of care-partner/resident dyads suggests that care-partner and resident agreement is poor and that care-partner ratings of compassionate care are not facsimiles of resident ratings.

Taken together, findings emerging from full sample analyses provide some evidence in support of the SCQ-CP's utility and credibility as a representative of resident ratings of compassionate care. SCQ-CP scores tend to covary with those of the SCQ with moderate consistency, but with poor agreement. In other words, care-partners tend to provide ratings that are similar to those of their affiliated resident, but not the same. This finding is convergent with previous research, which has found patient-proxy agreement to be consistently within the poor to moderate range (J. M. Jones et al., 2011; Novella et al., 2001; Scheepens et al., 2025). It is also compatible with other studies that have found that patient-proxy agreement depends on the type of information collected (Whiteman & Green, 1997), with larger discrepancies arising from ratings that require subjective abstraction (Novella et al., 2001; Raats et al., 2025; Vandijck et al.,

2009; von Essen, 2004). In this way, SCQ-CP scores can be considered a *comparable*, but not *interchangeable*, proxy of resident ratings of compassionate care.

Reproducibility refers to the extent to which a respondent's score on a measure remains consistent across repeated administrations. Under relatively constant conditions, an instrument should yield relatively stable measurements. Tools that produce variable measurements in the absence of any relevant change lack the reliability needed to have confidence in their use (Aldridge et al., 2017). Findings from this study suggest that the SCQ-CP boasts excellent reproducibility, meaning that prospective users of this tool should expect it to provide stable reflections of care-partner perceptions of compassionate care. These findings are congruent with those reported for the original SCQ (Sinclair et al., 2021) and lend support to their equivalence.

Limitations

The central limitation of this study is its small sample size. The identification and recruitment of care-partner/resident dyads presented a particular challenge due to the prevalence of cognitive impairment in long-term care settings. The resulting analytical sample of 15 dyads places important constraints on the precision of findings and the power to distinguish true effects from chance. In small sample sizes, the influence of individual participants is greater than in larger samples, a state of affairs which places smaller samples at greater risk of distortion in the presence of extreme or atypical participants. Small sample size also precludes the possibility of subsample analyses which, although not part of the analytical plan, might have yielded interesting exploratory insights and generated novel hypotheses for future research. Ultimately, this insufficiently powered sample means that the findings presented here, particularly those related to resident/care-partner association and agreement, should be treated as provisional.

This admittedly small sample was also drawn from two long-term care residences in Northwestern Ontario. This geographic concentration may not be representative of the general population of long-term care residents and care-partners, as it would fail to reflect differences in demographic characteristics that may shape healthcare expectations and perceptions, which in turn may influence ratings of compassionate care.

The present study employed a recruitment strategy which limits the generalizability of findings in a variety of ways. Firstly, convenience sampling presents the possibility that care-partners who opted to participate in the study may have a personal interest in the topic of compassionate care or harbour particularly high or low appraisals of this construct, which has the effect of yielding polarized ratings that may fail to capture the impressions of individuals who hold more moderate viewpoints. Convenience sampling of care-partners, a population that experiences high levels of stress and physical and emotional strain, also raises that possibility that the sample may be comprised of individuals who are or feel less burdened by their caregiving responsibilities in comparison to the wider cohort. By necessity, participation in the dyadic subgroup was limited to care-partners affiliated with long-term care residents who were cognitively intact, a criterion that inherently excludes the majority of long-term care residents and is therefore not reflective of the general long-term care population. Eligibility criteria also limited participation to care-partners who pay at least weekly visits to their loved one in long-term care. While this criterion served as a necessary benchmark of active participation in the care of a long-term care resident, it means that the present sample is overrepresented by individuals whose high level of engagement may bias their impressions of care. Taken together, additional research using randomized sampling methods at a range of long-term care sites over a wider geographical area is needed to produce more generalizable insights.

Clinical Implications

This study presents preliminary evidence to support the validity and reliability of a measure of compassionate care in long-term care settings that is adapted for use by care-partners. This constitutes an important step in the advancement of compassionate care research, which has been conspicuously absent from long-term care settings due to the unavailability of an appropriately adapted and empirically-derived measurement tool. By leveraging the perspective of informal care-partners who are intimately involved in the care of their loved ones, the SCQ-CP enables researchers to collect information about the delivery of compassion to long-term care residents who are no longer able to answer questions about their care, a population that was previously out of reach. Implementation of the SCQ-CP may shed light on the prevalence and degree of compassionate care in long-term care settings. Its theoretical basis on the Patient Compassion Model also permits a more granular understanding of compassionate care delivery by enabling inquiry into the extent to which different aspects of compassionate care are deployed in various settings. This knowledge, in turn, may lead to the development of policies, procedures, and training programs that are designed to foster, augment, and sustain compassionate care. By assisting in the advancement of compassionate care knowledge and practice, the SCQ-CP has the potential to improve long-term care experiences for future residents, care-partners, and healthcare providers.

Future Research

Of crucial importance, further research with larger dyadic samples of care-partners and residents is needed to clarify the relationship between scores on the original SCQ and those on the adapted SCQ-CP. A larger dyadic sample will also yield important insight into potential age, gender, and relationship-related differences in ratings of compassionate care.

Existing research suggests that agreement between care-partner and resident ratings on a variety of health and care-related measures may change over time (C. A. Jones & Feeny, 2005; Lapin et al., 2021; Rostagno et al., 2020), and as a function of patient health condition (J. M. Jones et al., 2011; Mcgrath et al., 2009). These findings present a compelling case for future longitudinal studies that explore potential fluctuations in resident/care-partner ratings over longer periods of time. The case for this kind of work is reinforced by research which identifies the transition to long-term care as an extended process of adjustment, typically lasting between 6 and 12 months (Brandburg, 2007) and characterized by behavioural, emotional, and relational changes for residents and care-partners alike (Afram et al., 2015; Crawford et al., 2015; Groenvynck et al., 2022; Lee et al., 2022; Sury et al., 2013). While it is reasonable to hypothesize that the turbulent nature of transition to long-term care may give rise to differences in expectation, experience, and perception that lead care-partners and residents to evaluate care differently, and that these differences may resolve as more harmonized understandings develop over time, research exploring this possibility appears to be scarce.

The development of the SCQ-CP was prompted by a compelling need to explore the construct of compassionate care in long-term care settings, and preliminary findings of its validity and reliability open the door to its use. An important next step in this field will be the use of the SCQ-CP to establish baseline levels of compassionate care and to track fluctuations across time and cognitive health status.

Conclusion

This work chronicles the initial adaptation, validation, and reliability testing of the SCQ-CP, a tool designed to measure compassion in long-term care settings from the perspective of informal care-partners. The content of the SCQ-CP was found to adequately capture the construct

of compassion. While additional testing is needed to establish more robust estimates of inter-rater reliability, SCQ-CP ratings of compassionate care were found to provide reasonable estimates of resident ratings, and its scores were found to be stable reflections of care-partner perception across time. While long-term care residents are best-placed to evaluate the quality of their care, in circumstances where this is not feasible, the present findings suggest that the perspective of care-partners may serve as an informative alternative. The Sinclair Compassion Questionnaire for Care-Partners opens the door to the empirical study of compassionate care in long-term care, a setting that was previously out of reach, and lays the foundation for clinical innovations that aim to bridge the compassion gap between care experiences that are adequate, and those that are excellent.

References

Afram, B., Verbeek, H., Bleijlevens, M. H. C., & Hamers, J. P. H. (2015). Needs of informal caregivers during transition from home towards institutional care in dementia: A systematic review of qualitative studies. *International Psychogeriatrics*, *27*(6), 891–902. https://doi.org/10.1017/S1041610214002154

Aldridge, V. K., Dovey, T. M., & Wade, A. (2017). Assessing test-retest reliability of psychological measures: Persistent methodological problems. *European Psychologist*, *22*(4), 207–218. https://doi.org/10.1027/1016-9040/a000298

Arieti, S. (1962). *American handbook of psychiatry*. Basic Books.

Attree, M. (2001). Patients' and relatives' experiences and perspectives of "Good" and "Not so Good" quality care. *Journal of Advanced Nursing*, *33*(4), 456–466. https://doi.org/10.1046/j.1365-2648.2001.01689.x

Barsade, S. G., & O'Neill, O. A. (2014). What's love got to do with it? A longitudinal study of the culture of compassionate love and employee and client outcomes in a long-term care setting. *Administrative Science Quarterly*, *59*(4), 551–598. https://doi.org/10.1177/0001839214538636

Bédard, M., Martin, N. J., Krueger, P., & Brazil, K. (2000). Assessing reproducibility of data obtained with instruments based on continuous measurements. *Experimental Aging Research*, *26*(4), 353–365. https://doi.org/10.1080/036107300750015741

Bertakis, K. D., & Azari, R. (2011). Patient-centered care is associated with decreased health care utilization. *Journal of the American Board of Family Medicine: JABFM*, *24*(3), 229–239. https://doi.org/10.3122/jabfm.2011.03.100170

Bond, C., Hui, A., Timmons, S., Wildbore, E., & Sinclair, S. (2024). Discourses of compassion from the margins of health care: The perspectives and experiences of people with a

mental health condition. *Journal of Mental Health*, *33*(1), 31–39. https://doi.org/10.1080/09638237.2022.2118692

Boss, H., MacInnis, C., Simon, R., Jackson, J., Lahtinen, M., & Sinclair, S. (2024). What role does compassion have on quality care ratings? A regression analysis and validation of the SCQ in emergency department patients. *BMC Emergency Medicine*, *24*(1), 124. https://doi.org/10.1186/s12873-024-01040-8

Bovero, A., Fraoni, A., Urru, S., Berchialla, P., Cotardo, F., Di Girolamo, I., Ostacoli, L., Sinclair, S., & Carletto, S. (2024). Measuring compassion in end-of-life cancer patients: The Italian validation of the Sinclair Compassion Questionnaire (SCQit). *Palliative & Supportive Care*, *22*(5), 1370–1377. https://doi.org/10.1017/S1478951524001202

Brandburg, G. L. (2007). Making the transition to nursing home life: A framework to help older adults adapt to the long-term care environment. *Journal of Gerontological Nursing*, *33*(6), 50–56. https://doi.org/10.3928/00989134-20070601-08

Brodaty, H., Woodward, M., Boundy, K., Ames, D., & Balshaw, R. (2014). Prevalence and Predictors of Burden in Caregivers of People with Dementia. *The American Journal of Geriatric Psychiatry, Caregiving*, *22*(8), 756–765. https://doi.org/10.1016/j.jagp.2013.05.004

Canada, P. H. A. of. (2021, July 14). *Aging and chronic diseases: A profile of Canadian seniors* [Education and awareness]. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/aging-chronic-diseases-profile-canadian-seniors-report.html

Chu, X. R., Jaggi, P., Louis, J. S., & Sinclair, S. (2023). Initial validation of a patient-reported compassion measure in a Mandarin-speaking long-termcare patient population. *Journal of Nursing Measurement*. https://doi.org/10.1891/JNM-2022-0097

Collins, D. (2003). Pretesting survey instruments: An overview of cognitive methods. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *12*(3), 229–238. https://doi.org/10.1023/a:1023254226592

Crawford, K., Digby, R., Bloomer, M., Tan, H., & Williams, A. (2015). Transitioning from caregiver to visitor in a long-term care facility: The experience of caregivers of people with dementia. *Aging & Mental Health*, *19*(8), 739–746. https://doi.org/10.1080/13607863.2014.962008

Crowther, J., Wilson, K. C. M., Horton, S., & Lloyd-Williams, M. (2013). Compassion in healthcare—Lessons from a qualitative study of the end of life care of people with dementia. *Journal of the Royal Society of Medicine*, *106*(12), 492–497. https://doi.org/10.1177/0141076813503593

Del Canale, S., Louis, D. Z., Maio, V., Wang, X., Rossi, G., Hojat, M., & Gonnella, J. S. (2012). The relationship between physician empathy and disease complications: An empirical study of primary care physicians and their diabetic patients in Parma, Italy. *Academic Medicine: Journal of the Association of American Medical Colleges*, *87*(9), 1243–1249. https://doi.org/10.1097/ACM.0b013e3182628fbf

Easter, D. W., & Beach, W. (2004). Competent patient care is dependent upon attending to empathic opportunities presented during interview sessions. *Current Surgery*, *61*(3), 313–318. https://doi.org/10.1016/j.cursur.2003.12.006

Eritz, H., Hadjistavropoulos, T., Williams, J., Kroeker, K., Martin, R. R., Lix, L. M., & Hunter, P. V. (2016). A life history intervention for individuals with dementia: A randomised controlled trial examining nursing staff empathy, perceived patient personhood and aggressive behaviours. *Ageing & Society*, *36*(10), 2061–2089. https://doi.org/10.1017/S0144686X15000902

Flocke, S. A., Miller, W. L., & Crabtree, B. F. (2002). Relationships between physician practice style, patient satisfaction, and attributes of primary care. *The Journal of Family Practice*, *51*(10), 835–840.

Fogarty, L. A., Curbow, B. A., Wingard, J. R., McDonnell, K., & Somerfield, M. R. (1999). Can 40 seconds of compassion reduce patient anxiety? *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, *17*(1), 371–379. https://doi.org/10.1200/JCO.1999.17.1.371

Francis, R. (2010, February). *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 to March 2009*. GOV.UK. https://www.gov.uk/government/publications/independent-inquiry-into-care-provided-by-mid-staffordshire-nhs-foundation-trust-january-2001-to-march-2009

Francis, R. (2013, February). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. GOV.UK. https://www.gov.uk/government/publications/report-of-the-mid-staffordshire-nhs-foundation-trust-public-inquiry

Frost, P. J. (1999). Why compassion counts! *Journal of Management Inquiry*, *8*(2), 127–133. https://doi.org/10.1177/105649269982004

Garrett, P. W., Dickson, H. G., Whelan, A. K., & Roberto-Forero, null. (2008). What do non-English-speaking patients value in acute care? Cultural competency from the patient's

perspective: a qualitative study. *Ethnicity & Health*, *13*(5), 479–496. https://doi.org/10.1080/13557850802035236

Goetz, J. L., Keltner, D., & Simon-Thomas, E. (2010). Compassion: An evolutionary analysis and empirical review. *Psychological Bulletin*, *136*(3), 351–374. https://doi.org/10.1037/a0018807

Goodwin, L. D. (2001). Interrater Agreement and Reliability. *Measurement in Physical Education and Exercise Science*, *5*(1), 13–34. https://doi.org/10.1207/S15327841MPEE0501_2

Government of Canada, S. C. (2019, February 8). *Older adults and population aging statistics*. https://www.statcan.gc.ca/en/subjects-start/older_adults_and_population_aging

Government of Canada, S. C. (2021, September 16). *The Daily—A profile of nursing and residential care facilities, 2019*. https://www150.statcan.gc.ca/n1/daily-quotidien/210916/dq210916c-eng.htm

Government of Canada, S. C. (2022, April 27). *A portrait of Canada's growing population aged 85 and older from the 2021 Census*. https://www12.statcan.gc.ca/census-recensement/2021/as-sa/98-200-x/2021004/98-200-x2021004-eng.cfm

Graber, D. R., & Mitcham, M. D. (2004). Compassionate clinicians: Take patient care beyond the ordinary. *Holistic Nursing Practice*, *18*(2), 87–94. https://doi.org/10.1097/00004650-200403000-00006

Groenvynck, L., de Boer, B., Beaulen, A., de Vries, E., Hamers, J. P. H., van Achterberg, T., van Rossum, E., Khemai, C., Meijers, J. M. M., & Verbeek, H. (2022). The paradoxes experienced by informal caregivers of people with dementia during the transition from

home to a nursing home. *Age and Ageing*, *51*(2), afab241. https://doi.org/10.1093/ageing/afab241

Hakimjavadi, R., Yin, C. Y., Scott, M., Talarico, R., Ramsay, T., Webber, C., Manuel, D., Moledina, A., Hsu, A. T., Fung, C., Kaasalainen, S., Kierulf, J., Molnar, F., Shamon, S., Robert, B., Ronksley, P. E., Tanuseputro, P., Wilson, K., & Kobewka, D. (2025). Cognitive and functional decline among long-term care residents. *JAMA Network Open*, *8*(4), e255635. https://doi.org/10.1001/jamanetworkopen.2025.5635

Hawkins, M., & Nadel, J. (2022). *How compassion can transform our politics, economy, and society*. Routledge.

Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., Shortt, S., Tranmer, J., Lazar, N., Kutsogiannis, J., & Lam, M. (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *CMAJ : Canadian Medical Association Journal*, *174*(5), 627–633. https://doi.org/10.1503/cmaj.050626

Heyland, D. K., Jiang, X., Day, A. G., Cohen, S. R., & Canadian Researchers at the End of Life Network (CARENET). (2013). The development and validation of a shorter version of the Canadian Health Care Evaluation Project Questionnaire (CANHELP Lite): A novel tool to measure patient and family satisfaction with end-of-life care. *Journal of Pain and Symptom Management*, *46*(2), 289–297. https://doi.org/10.1016/j.jpainsymman.2012.07.012

Himmelfarb, G. (2001). The idea of compassion: The British vs. the French enlightenment. *Public Interest*, (145), 3–24.

Jones, C. A., & Feeny, D. H. (2005). Agreement Between Patient and Proxy Responses of Health-Related Quality of Life After Hip Fracture. *Journal of the American Geriatrics Society*, *53*(7), 1227–1233. https://doi.org/10.1111/j.1532-5415.2005.53374.x

Jones, J. M., McPherson, C. J., Zimmermann, C., Rodin, G., Le, L. W., & Cohen, S. R. (2011). Assessing Agreement Between Terminally Ill Cancer Patients' Reports of Their Quality of Life and Family Caregiver and Palliative Care Physician Proxy Ratings. *Journal of Pain and Symptom Management*, *42*(3), 354–365. https://doi.org/10.1016/j.jpainsymman.2010.11.018

Kahn, W. A. (1993). Caring for the caregivers: Patterns of organizational caregiving. *Administrative Science Quarterly*, *38*(4), 539–563. https://doi.org/10.2307/2393336

Kanov, J. M., Maitlis, S., Worline, M. C., Dutton, J. E., Frost, P. J., & Lilius, J. M. (2004). Compassion in organizational Life. *American Behavioral Scientist*, *47*(6), 808–827. https://doi.org/10.1177/0002764203260211

Lapin, B. R., Thompson, N. R., Schuster, A., & Katzan, I. L. (2021). Patient-proxy agreement on change in acute stroke patient-reported outcome measures: A prospective study. *Journal of Patient-Reported Outcomes*, *5*(1), 53. https://doi.org/10.1186/s41687-021-00329-7

Lee, K., Chung, J., Meyer, K. N., & Dionne-Odom, J. N. (2022). Unmet needs and health-related quality of life of dementia family caregivers transitioning from home to long-term care: A scoping review. *Geriatric Nursing*, *43*, 254–264. https://doi.org/10.1016/j.gerinurse.2021.12.005

Levinson, W., Roter, D. L., Mullooly, J. P., Dull, V. T., & Frankel, R. M. (1997). Physician-patient communication. The relationship with malpractice claims among primary care

physicians and surgeons. *JAMA*, *277*(7), 553–559. https://doi.org/10.1001/jama.277.7.553

Lilius, J., Worline, M., Dutton, J., Kanov, J., Frost, P., & Maitlis, S. (2003, August 1). *What good is compassion at work?* [Paper presentation]. National Meeting of the Academy of Management, Seattle, WA, United States.

Lown, B. A., Rosen, J., & Marttila, J. (2011). An agenda for improving compassionate care: A survey shows about half of patients say such care is missing. *Health Affairs (Project Hope)*, *30*(9), 1772–1778. https://doi.org/10.1377/hlthaff.2011.0539

Mcgrath, C., Mcmillan, A. S., Zhu, H. W., & Li, L. S. W. (2009). Agreement between patient and proxy assessments of oral health-related quality of life after stroke: An observational longitudinal study. *Journal of Oral Rehabilitation*, *36*(4), 264–270. https://doi.org/10.1111/j.1365-2842.2009.01941.x

Nadin, S., Miandad, M. A., Kelley, M. L., Marcella, J., & Heyland, D. K. (2017). Measuring family members' satisfaction with end-of-life care in long-term care: Adaptaton of the CANHELP Lite Questionnaire. *BioMed Research International*, *2017*, 4621592. https://doi.org/10.1155/2017/4621592

Ng, R., Lane, N., Tanuseputro, P., Mojaverian, N., Talarico, R., Wodchis, W. P., Bronskill, S. E., & Hsu, A. T. (2020). Increasing complexity of new nursing home residents in Ontario, Canada: A serial cross-sectional study. *Journal of the American Geriatrics Society*, *68*(6), 1293–1300. https://doi.org/10.1111/jgs.16394

Novella, J. L., Jochum, C., Jolly, D., Morrone, I., Ankri, J., Bureau, F., & Blanchard, F. (2001). Agreement between patients' and proxies' reports of quality of lifein Alzheimer's

disease. *Quality of Life Research*, *10*(5), 443–452. https://doi.org/10.1023/A:1012522013817

Ontario's Long-Term Care COVID-19 Commission (with Marrocco, F. N.). (2021). *Ontario's Long-Term Care COVID-19 Commission: Final Report.* Long-Term Care COVID-19 Commission.

O'Toole, J., Bamberry, L., & Montague, A. (2021). Residential aged care leadership in Australia-Time for a compassionate approach: A qualitative analysis of key leader skills and attributes. *Journal of Nursing Management*, *29*(7), 2018–2027. https://doi.org/10.1111/jonm.13335

Pavlova, A., Paine, S.-J., Sinclair, S., O'Callaghan, A., & Consedine, N. S. (2023). Working in value-discrepant environments inhibits clinicians' ability to provide compassion and reduces well-being: A cross-sectional study. *Journal of Internal Medicine*, *293*(6), 704–723. https://doi.org/10.1111/joim.13615

Raats, J. H., Ponds, N. H. M., Brameier, D. T., Bain, P. A., Schuijt, H. J., van der Velde, D., & Weaver, M. J. (2025). Agreement between patient- and proxy-reported outcome measures in adult musculoskeletal trauma and injury: A scoping review. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *34*(1), 89–99. https://doi.org/10.1007/s11136-024-03766-1

Rafferty, A. M., & Leary, A. (2023). Nursing notes on a scandal. *Future Healthcare Journal*, *10*(1), 3–6. https://doi.org/10.7861/fhj.2023-FR102

Riggs, J. S., Woodby, L. L., Burgio, K. L., Bailey, F. A., & Williams, B. R. (2014). "Don't get weak in your compassion": Bereaved next of kin's suggestions for improving end-of-life

care in Veterans Affairs Medical Centers. *Journal of the American Geriatrics Society*, *62*(4), 642–648. https://doi.org/10.1111/jgs.12764

Rostagno, E., Marchetti, A., Bergadano, A., Canesi, M., Crotti Partel, M., Rondelli, R., De Marinis, M. G., & Piredda, M. (2020). Concordance between paediatric self-reports and parent proxy reports on fatigue: A multicentre prospective longitudinal study. *European Journal of Oncology Nursing*, *49*, 101829. https://doi.org/10.1016/j.ejon.2020.101829

Royal Commission into Aged Care Quality and Safety (with Pagone, T., & Briggs, L.). (2021). *Final Report: Care, Dignity and Respect* (Vol. 1). Royal Commission into Aged Care Quality and Safety. https://www.royalcommission.gov.au/aged-care/final-report

Scheepens, J. C. C., Boele, F. W., & Koekkoek, J. A. F. (2025). Patient-proxy agreement on health-related quality of life assessment in cancer patients. *Current Opinion in Oncology*, *37*(6), 603–610. https://doi.org/10.1097/CCO.0000000000001189

Shaltout, H. A., Tooze, J. A., Rosenberger, E., & Kemper, K. J. (2012). Time, touch, and compassion: Effects on autonomic nervous system and well-being. *Explore (New York, N.Y.)*, *8*(3), 177–184. https://doi.org/10.1016/j.explore.2012.02.001

Sinclair, S., Beamer, K., Hack, T. F., McClement, S., Raffin Bouchal, S., Chochinov, H. M., & Hagen, N. A. (2017). Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences. *Palliative Medicine*, *31*(5), 437–447. https://doi.org/10.1177/0269216316663499

Sinclair, S., Bouchal, S. R., Schulte, F., M. T. Guilcher, G., Kuhn, S., Rapoport, A., Punnett, A., Fernandez, C. V., Letourneau, N., & Chung, J. (2021). Compassion in pediatric oncology: A patient, parent and healthcare provider empirical model. *Psycho-Oncology*, *30*(10), 1728–1738. https://doi.org/10.1002/pon.5737

Sinclair, S., Dhingra, S., Bouchal, S. R., MacInnis, C., Harris, D., Roze des Ordons, A., & Pesut, B. (2024). The initial validation of an evidence-informed, competency-based, applied compassion training (EnACT) program: A multimethod study. *BMC Medical Education*, *24*(1), 686. https://doi.org/10.1186/s12909-024-05663-0

Sinclair, S., Hack, T. F., MacInnis, C. C., Jaggi, P., Boss, H., McClement, S., Sinnarajah, A., Thompson, G., & COMPASS Research Team. (2021). Development and validation of a patient-reported measure of compassion in healthcare: The Sinclair Compassion Questionnaire (SCQ). *BMJ Open*, *11*(6), e045988. https://doi.org/10.1136/bmjopen-2020-045988

Sinclair, S., Hack, T. F., McClement, S., Raffin-Bouchal, S., Chochinov, H. M., & Hagen, N. A. (2020). Healthcare providers perspectives on compassion training: A grounded theory study. *BMC Medical Education*, *20*(1), 249. https://doi.org/10.1186/s12909-020-02164-8

Sinclair, S., Hack, T. F., Raffin-Bouchal, S., McClement, S., Stajduhar, K., Singh, P., Hagen, N. A., Sinnarajah, A., & Chochinov, H. M. (2018). What are healthcare providers' understandings and experiences of compassion? The healthcare compassion model: a grounded theory study of healthcare providers in Canada. *BMJ Open*, *8*(3), e019701. https://doi.org/10.1136/bmjopen-2017-019701

Sinclair, S., Harris, D., Kondejewski, J., Roze des Ordons, A. L., Jaggi, P., & Hack, T. F. (2023). Program leaders' and educators' perspectives on the factors impacting the implementation and sustainment of compassion training programs: A qualitative study. *Teaching and Learning in Medicine*, *35*(1), 21–36. https://doi.org/10.1080/10401334.2021.2017941

Sinclair, S., Jaggi, P., Bouchal, S. R., Kuhn, S., Schulte, F., Guilcher, G. M. T., Rapoport, A., Punnett, A., Fernandez, C. V., Letourneau, N., & Chung, J. (2022). Implementing compassion in pediatric healthcare: A qualitative study of Canadian patients', parents', and healthcare providers' perspectives. *Journal of Pediatric Nursing*, *62*, e103–e112. https://doi.org/10.1016/j.pedn.2021.08.001

Sinclair, S., Jaggi, P., Hack, T. F., McClement, S. E., & Cuthbertson, L. (2020). A practical guide for item generation in measure development: Insights from the development of a patient-reported experience measure of compassion. *Journal of Nursing Measurement*, *28*(1), 138–156. https://doi.org/10.1891/JNM-D-19-00020

Sinclair, S., Jaggi, P., Hack, T. F., McClement, S. E., Raffin-Bouchal, S., & Singh, P. (2018). Assessing the credibility and transferability of the patient compassion model in non-cancer palliative populations. *BMC Palliative Care*, *17*(1), Article 1. https://doi.org/10.1186/s12904-018-0358-5

Sinclair, S., Jaggi, P., Hack, T. F., Russell, L., McClement, S. E., Cuthbertson, L., Selman, L. E., & Leget, C. (2020). Initial validation of a patient-reported measure of compassion: Determining the content validity and clinical sensibility among patients living with a life-limiting and incurable illness. *The Patient - Patient-Centered Outcomes Research*, *13*(3), 327–337. https://doi.org/10.1007/s40271-020-00409-8

Sinclair, S., Kondejewski, J., Hack, T. F., Boss, H. C. D., & MacInnis, C. C. (2022). What is the most valid and reliable compassion measure in healthcare? An updated comprehensive and critical review. *The Patient*, *15*(4), 399–421. https://doi.org/10.1007/s40271-022-00571-1

Sinclair, S., Kondejewski, J., Jaggi, P., Dennett, L., Roze des Ordons, A. L., & Hack, T. F. (2021). What is the state of compassion education? A systematic review of compassion training in health care. *Academic Medicine*, *96*(7), 1057. https://doi.org/10.1097/ACM.0000000000004114

Sinclair, S., Kondejewski, J., Jaggi, P., Roze des Ordons, A. L., Kassam, A., Hayden, K. A., Harris, D., & Hack, T. F. (2021). What works for whom in compassion training programs offered to practicing healthcare providers: A realist review. *BMC Medical Education*, *21*(1), 455. https://doi.org/10.1186/s12909-021-02863-w

Sinclair, S., Kondejewski, J., Schulte, F., Letourneau, N., Kuhn, S., Raffin-Bouchal, S., Guilcher, G. M. T., & Strother, D. (2020). Compassion in pediatric healthcare: A scoping review. *Journal of Pediatric Nursing*, *51*, 57–66. https://doi.org/10.1016/j.pedn.2019.12.009

Sinclair, S., McClement, S., Raffin-Bouchal, S., Hack, T. F., Hagen, N. A., McConnell, S., & Chochinov, H. M. (2016). Compassion in health care: An empirical model. *Journal of Pain and Symptom Management*, *51*(2), 193–203. https://doi.org/10.1016/j.jpainsymman.2015.10.009

Sinclair, S., Norris, J. M., McConnell, S. J., Chochinov, H. M., Hack, T. F., Hagen, N. A., McClement, S., & Bouchal, S. R. (2016). Compassion: A scoping review of the healthcare literature. *BMC Palliative Care*, *15*, 6. https://doi.org/10.1186/s12904-016-0080-0

Sinclair, S., Raffin-Bouchal, S., Venturato, L., Mijovic-Kondejewski, J., & Smith-MacDonald, L. (2017). Compassion fatigue: A meta-narrative review of the healthcare literature. *International Journal of Nursing Studies*, *69*, 9–24. https://doi.org/10.1016/j.ijnurstu.2017.01.003

Sinclair, S., Russell, L. B., Hack, T. F., Kondejewski, J., & Sawatzky, R. (2017). Measuring compassion in healthcare: A comprehensive and critical review. *The Patient*, *10*(4), 389–405. https://doi.org/10.1007/s40271-016-0209-5

Sinclair, S., Torres, M.-B., Raffin-Bouchal, S., Hack, T. F., McClement, S., Hagen, N. A., & Chochinov, H. M. (2016). Compassion training in healthcare: What are patients' perspectives on training healthcare providers? *BMC Medical Education*, *16*(1), 169–169. https://doi.org/10.1186/s12909-016-0695-0

Singh, P., King-Shier, K., & Sinclair, S. (2018). The colours and contours of compassion: A systematic review of the perspectives of compassion among ethnically diverse patients and healthcare providers. *PLOS ONE*, *13*(5), e0197261. https://doi.org/10.1371/journal.pone.0197261

Smith-MacDonald, L., Venturato, L., Hunter, P., Kaasalainen, S., Sussman, T., McCleary, L., Thompson, G., Wickson-Griffiths, A., & Sinclair, S. (2019). Perspectives and experiences of compassion in long-term care facilities within Canada: A qualitative study of patients, family members and health care providers. *BMC Geriatrics*, *19*(1), 128. https://doi.org/10.1186/s12877-019-1135-x

Soler-Gonzalez, J., San-Martín, M., Delgado-Bolton, R., & Vivanco, L. (2017). Human connections and their roles in the occupational well-being of healthcare professionals: A study on loneliness and empathy. *Frontiers in Psychology*, *8*, 1475. https://doi.org/10.3389/fpsyg.2017.01475

Soto-Rubio, A., Andreu, Y., Gil-Juliá, B., Picazo, C., Murgui, S., MacInnis, C. C., & Sinclair, S. (2024). Adaptation and validation of a patient-reported compassion measure in the Spanish population: The Spanish version of the Sinclair Compassion Questionnaire

(SCQesp). *Research in Nursing & Health*, *47*(3), 344–355. https://doi.org/10.1002/nur.22373

Soto-Rubio, A., & Sinclair, S. (2018). In defense of sympathy, in consideration of empathy, and in praise of compassion: A history of the present. *Journal of Pain and Symptom Management*, *55*(5), 1428–1434. https://doi.org/10.1016/j.jpainsymman.2017.12.478

Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: A review. *CMAJ: Canadian Medical Association Journal = Journal de l'Association Medicale Canadienne*, *152*(9), 1423–1433.

Strauss, M. E., & Smith, G. T. (2009). Construct Validity: Advances in Theory and Methodology. *Annual Review of Clinical Psychology*, *5*(Volume 5, 2009), 1–25. https://doi.org/10.1146/annurev.clinpsy.032408.153639

Streiner, D. L. (2003). Starting at the Beginning: An Introduction to Coefficient Alpha and Internal Consistency. *Journal of Personality Assessment*, *80*(1), 99–103. https://doi.org/10.1207/S15327752JPA8001_18

Sury, L., Burns, K., & Brodaty, H. (2013). Moving in: Adjustment of people living with dementia going into a nursing home and their families. *International Psychogeriatrics*, *25*(6), 867–876. https://doi.org/10.1017/S1041610213000057

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education*, *2*, 53–55. https://doi.org/10.5116/ijme.4dfb.8dfd

This is Long-Term Care 2018. (2018). Ontario Long Term Care Association.

Tinsley, H. E., & Weiss, D. J. (1975). Interrater reliability and agreement of subjective judgments. *Journal of Counseling Psychology*, *22*(4), 358–376. https://doi.org/10.1037/h0076640

Vandijck, D., Oeyen, S., Costers, S., Annemans, L., & Decruyenaere, J. (2009). Agreement between patient and proxy assessment of health-related quality of life before intensive care unit admission. *Value in Health*, *12*(7), A397–A397. https://doi.org/10.1016/S1098-3015(10)74957-3

Von Dietze, E., & Orb, A. (2000). Compassionate care: A moral dimension of nursing. *Nursing Inquiry*, *7*(3), 166–174. https://doi.org/10.1046/j.1440-1800.2000.00065.x

von Essen, L. (2004). Proxy ratings of patient quality of life—Factors related to patient-proxy agreement. *Acta Oncologica*, *43*(3), 229–234. https://doi.org/10.1080/02841860410029357

Whiteman, D., & Green, A. (1997). Wherein lies the truth? Assessment of agreement between parent proxy and child respondents. *International Journal of Epidemiology*, *26*(4), 855–859. https://doi.org/10.1093/ije/26.4.855

Appendix A

Sinclair Compassion Questionnaire (SCQ)

The Sinclair Compassion Questionnaire (SCQ)

This questionnaire has been developed to ask you about your experience with the following aspects of compassionate care. Please carefully read each question and rate your level of agreement with it.

Instructions:
In thinking about your Healthcare Providers over the past 7 days, please rate the following:

1. My Healthcare Providers made me feel cared for.

○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree

2. My Healthcare Providers showed genuine concern for me.

○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree

3. My Healthcare Providers communicated with me in a sensitive manner.

○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree

4. I felt that my Healthcare Providers were attentive to me.

○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree

5. My Healthcare Providers provided me with comfort.

○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree

6. My Healthcare Providers were very supportive when they talked with me.

○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree

7. My Healthcare Providers provided care in a gentle manner.

○Strongly disagree ○Disagree ○Neutral ○Agree ○Strongly agree

8. My Healthcare Providers spoke to me with kindness.

○Strongly disagree ○Disagree ○Neutral ○Agree ○Strongly agree

9. My Healthcare Providers saw me as a person and not just as a patient.

○Strongly disagree ○Disagree ○Neutral ○Agree ○Strongly agree

10. My Healthcare Providers behaved in a caring way.

○Strongly disagree ○Disagree ○Neutral ○Agree ○Strongly agree

11. My Healthcare Providers really understood my needs.

○Strongly disagree ○Disagree ○Neutral ○Agree ○Strongly agree

12. I had a good relationship with my Healthcare Providers.

○Strongly disagree ○Disagree ○Neutral ○Agree ○Strongly agree

13. My Healthcare Providers were able to see things from my perspective.

○Strongly disagree ○Disagree ○Neutral ○Agree ○Strongly agree

14. My Healthcare Providers had a warm presence.

○Strongly disagree ○Disagree ○Neutral ○Agree ○Strongly agree

15. I felt that my Healthcare Providers were sincere.

○Strongly disagree ○Disagree ○Neutral ○Agree ○Strongly agree

Appendix B

Sinclair Compassion Questionnaire for Care-Partners (SCQ-CP)

The Sinclair Compassion Questionnaire – Care Partners (SCQ-CP)

This questionnaire has been developed to ask you about your experience with the following aspects of compassionate care involving Healthcare Providers. By Healthcare Providers, we mean all staff who interacted directly with the resident (for example, nurses, personal support workers, housekeepers). Please carefully read each question and rate your level of agreement with it.

Instructions:

Overall, in thinking about the resident's Healthcare Providers over the past 7 days, please rate the following:

1. **The Healthcare Providers made the resident feel cared for.**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

2. **The Healthcare Providers showed genuine concern for the resident.**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

3. **The Healthcare Providers communicated with the resident in a sensitive manner.**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

4. **The Healthcare Providers were attentive to the resident.**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

5. **The Healthcare Providers provided the resident with comfort.**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

6. **The Healthcare Providers were very supportive when they talked with the resident.**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

Instructions:

Overall, in thinking about the resident's Healthcare Providers over the past 7 days, please rate the following:

7. The Healthcare Providers provided care to the resident in a gentle manner.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

8. The Healthcare Providers spoke to the resident with kindness.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

9. The Healthcare Providers saw the resident as a person, and not just as a patient.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

10. The Healthcare Providers behaved in a caring way toward the resident.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

11. The Healthcare Providers really understood the resident's needs.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

12. The Healthcare Providers had a good relationship with the resident.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

13. The Healthcare Providers were able to see things from the resident's perspective.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

14. The Healthcare Providers had a warm presence when interacting with the resident.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

15. The Healthcare Providers were sincere.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

Appendix C

Canadian Health Care Evaluation Project (CANHELP) Lite Long-Term Care Questionnaire

CANHELP Lite Long-Term Care Questionnaire - Revised

Not at all Satisfied	Not very Satisfied	Somewhat Satisfied	Very Satisfied	Completely Satisfied	Unsure	Consider the care the resident received at SJCG **over the past 7 days** and tell us **HOW SATISFIED** you are right now with that aspect of care. Please circle the appropriate number that best reflects your answer.
Satisfaction: Characteristics of the Long Term Care Health Provider						
1	2	3	4	5	9	1. The Healthcare Providers looking after the resident were compassionate and supportive of them.
1	2	3	4	5	9	2. The Healthcare Providers looking after the resident are compassionate and supportive of you.
Satisfaction: Illness Management						
1	2	3	4	5	9	3. The tests are done and the treatments are given for the resident's medical problems in the long-term care home.
1	2	3	4	5	9	4. The physical symptoms (for example: pain, shortness of breath, nausea) the resident has are adequately assessed and controlled.
1	2	3	4	5	9	5. The emotional problems (for example: depression, anxiety) the resident has are adequately assessed and controlled.
1	2	3	4	5	9	6. The resident receives help with

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						personal care (for example: bathing, toileting, dressing, eating) when needed.
1	2	3	4	5	9	7. The resident received good care when you were not able to be with him/her.
1	2	3	4	5	9	8. The Healthcare Providers worked together as a team to look after the resident.
1	2	3	4	5	9	9. You are able to manage the financial costs associated with the resident's long-term care.
1	2	3	4	5	9	10. The environment or the surroundings in which the resident received care was calm and restful.
1	2	3	4	5	9	11. The care and treatment the resident received was consistent with their wishes.
Satisfaction: *Communication and Decision Making*						
1	2	3	4	5	9	12. The Healthcare Providers explained things related to the resident's illness in a straightforward, honest manner.
1	2	3	4	5	9	13. You received consistent information about the resident's condition from all the Healthcare Providers looking after them.
1	2	3	4	5	9	14. The Healthcare Providers listened to what you said.
1	2	3	4	5	9	15. You discussed options with the nursing staff about whether the resident would be transferred to hospital or cared for in the long-

St. Joseph's Care Group

Care Compassion Commitment

						term care home if they were to get worse.
Satisfaction: *Relationship with Doctors*						
1	2	3	4	5	9	16. The doctor(s) takes a personal interest in the resident.
1	2	3	4	5	9	17. The doctor(s) were available when you or the resident needed them (by phone or in-person).
1	2	3	4	5	9	18. You had trust and confidence in the doctor(s) who looked after the resident.