

BMJ Open Defining compassion in the digital health age: protocol for a scoping review

David Wiljer,^{1,2,3,4,5} Rebecca Charow,¹ Helen Costin,^{4,6} Lydia Sequeira,^{2,5} Melanie Anderson,⁷ Gillian Strudwick,^{2,5} Tim Tripp,⁷ Allison Crawford^{3,5,6}

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¹UHN Digital, University Health Network, Toronto, Ontario, Canada

²Institute of Health Policy Management and Evaluation, University of Toronto, Toronto, Ontario, Canada

³Department of Psychiatry, University of Toronto, Toronto, Ontario, Canada

⁴The Wilson Centre, University Health Network, Toronto, Ontario, Canada

⁵Centre for Addiction and Mental Health, Toronto, Ontario, Canada

⁶Medical Psychiatry Alliance, University of Toronto, Toronto, Ontario, Canada

⁷Library and Information Services, University Health Network, Toronto, Ontario, Canada

Correspondence to

Dr David Wiljer;
david.wiljer@uhn.ca

ABSTRACT

Introduction The notion of compassion and compassionate care is playing an increasingly important role in health professional education and in the delivery of high-quality healthcare. Digital contexts, however, are not considered in the conceptualisation of compassionate care, nor is there guidance on how compassionate care is to be exercised while using digital health technologies. The widespread diffusion of digital health technologies provides new contexts for compassionate care, with both opportunities for new forms and instantiations of compassion as well as new challenges. How compassion is both understood and enacted within this evolving, digital realm has not been synthesised.

Methods and analysis This scoping review protocol follows Arksey and O'Malley's methodology to examine dimensions of compassionate professional practice when digital technologies are integrated into clinical care. Relevant peer-reviewed literature will be identified using a search strategy developed by medical librarians, which applies to six databases of medical, computer and information systems disciplines. Eligibility of articles will be determined using the two-stage screening process consisting of (1) title and abstract scan, and (2) full-text review. Screening, abstracting and charting will be conducted by two independent reviewers, with a third reviewer available for resolution when consensus is not achieved. In order to look at the range of current research in this area, extracted data will be thematically analysed and validated by content experts. Descriptive statistics will be calculated where necessary.

Ethics and dissemination Research ethics approval and consent to participate is not required for this scoping review. The results of the review will inform resource development and strategy for Associated Medical Services (AMS) Healthcare, a Canadian charitable organisation at the forefront of advancing research and leadership development in health and humanities, as part of the AMS Phoenix Project: A Call to Caring, particularly for digital professionalism frameworks so that they are inclusive of a compassion competency.

INTRODUCTION

Compassion is a topic of great interest in recent healthcare research.¹ Scholars, health professionals and patients across healthcare disciplines have agreed that compassion in health services is a necessary and critical component of healing.²⁻⁴ This value is reflected widely.

Strengths and limitations of this study

- Findings from this review will contribute to the development of a definition of compassionate care within the context of digital health.
- The methodology includes a transparent and rigorous study design grounded in established, evidence-based frameworks (Arksey and O'Malley), a systematic search strategy developed collaboratively and iteratively with a medical librarian, and standardised charting using a theory-oriented framework.
- Our team is composed of health services researchers from both the compassionate care and digital health fields, including senior investigators who are content experts.
- No quality assessments will be completed on the included studies since our objective is to provide a baseline understanding of the state of compassion in the field of digital healthcare innovations.
- Findings will be limited to articles written in English, and thus subject to cultural bias.

An imperative of the Canadian Medical Association, for example, specifies that our care system must 'optimise function and compassionate relief of suffering'.⁵ Compassionate practice is similarly reflected in paradigms of health education. As health education shifts towards competency-based frameworks globally, the quality and practice of compassion become milestones of professionalism and one's role as a 'communicator', as outlined by the American Association of Medical Colleges,⁶ Accreditation Council for Graduate Medical Education,⁷ CanMEDS framework⁸ and others.⁹

Despite the prevalence of compassion in the current discourse, there is a growing disparity between what we know about the healing benefits of compassion in health services and the feedback from service users and providers about the lack of compassion in the current health system. There have been numerous conceptualisations of compassion across healthcare disciplines including nursing, social work, psychology

and medicine,^{10–12} yet commonalities exist across definitions, including (1) an initial recognition of suffering by an individual followed by either (2) an emotional or (3) operative response to this suffering.¹² For example, the Oxford Handbook of Compassion Science proposes that compassion is a ‘discreet and evolved emotional experience’ that an individual has on recognising and wanting to alleviate the suffering or perceived unmet needs of another.¹³ This working definition of compassion involves several distinct components including the (1) awareness of another’s experience of suffering or need, (2) feeling ‘moved’ and (3) recognising this feeling as a response to the other’s need; (4) making a judgement that the other is suffering; and (5) engaging in a behaviour in an attempt to alleviate the suffering.¹³ Some scholars have suggested that the shift towards efficiency in healthcare service poses limitations to the time that compassionate practice requires.^{14 15}

Digital technologies, especially modalities for communication, are one of the sets of tools increasingly leveraged to facilitate this shift towards efficiency and accessibility.¹⁶ Within health service improvement, this intersection of technology and healthcare gave rise to the discipline of ‘eHealth’.¹⁷ A widely used definition of eHealth states that this is “an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies”.¹⁸ Over time, eHealth evolved to encompass all digital modalities involved within healthcare, including but not limited to telemedicine, electronic medical records and mobile health, leading to the larger umbrella term of ‘digital health’. Digital health, which refers to the ‘use of information technology and electronic communication tools within the delivery of healthcare services’, has accelerated its adoption over the past two decades.¹⁹ Through implementing electronic health records and using mobile applications, digital health has led to improved quality, safety and efficiency in healthcare.²⁰ These technologies have propelled all areas of health communication, including knowledge transfer between patients and health professionals, education, decision support and health promotion.²¹ For some patients, the increased anonymity and distance can support better empathic and honest communication than in-person consults, especially within online healthcare communities.²² Digital health has also improved accessibility of health services and the skills of health professionals to rural and remote communities and those patients with limited mobility.²³ However, although there may be potential benefits, digital health represents a transformational shift in the context, process and manner that care is delivered. With the transitions in care including mobile computerised nursing stations, touch screens, various automated processes and services, and barcode medication administration, a new mediating entity emerges in the traditional patient–provider relationship and compassionate care–technology.^{24 25} This technology can be as simple as a user interface for

automatic self-registration or an artificial intelligence robot that contributes to bedside care.

As we move beyond simple automation of healthcare processes, health technologies will increase the potential for patient engagement and activation, and change the nature of the therapeutic relationship. Through mobile apps, patients have the opportunity to become more effective partners in their care, with increased access to their data and ability to track their symptoms more accurately.²⁶ Through web-based platforms, patients are electing to engage in computer-based communication with their providers²⁷ as well as psychological interventions.^{28 29} This widespread diffusion of digital health provokes a new discourse on information management, dissemination and control.³⁰ With this increased patient engagement, the boundaries of professional ethics and expectations are changing as the capabilities for real-time two-way communication between health professionals and patients are now available through email, texting, in-application chats and video-calling.³¹ Through the removal of geographical and temporal barriers, information and resources are available anytime, anywhere. This increase of availability can potentially lead to an increased workload and information overload by health professionals, who have to grapple with knowing when to ‘turn off’.³² Moreover, communication and care through digital means could lack emotional signals and cues to convey empathy that may be present in the traditional, in-person encounter. This has led to a call for integrating digital empathy into the curriculum of health professionals.³³ Shifting medical practice requires new competencies to ensure that providers are able to sustain a patient-centred approach through creatively and flexibly using digital health applications while maintaining attention to the patient’s narrative.³³ Improved communication skills, self-reflection and reflexivity are examples of focused competencies to help professionals examine their interactions and express empathy and compassion in a digital world.³⁴

In recent publications, the Associated Medical Services (AMS) suggested that education for healthcare students integrate the use of new technologies into practice, as well as promote compassionate care and the humane aspects of care.^{35 36} Although work is underway to define what competencies are necessary for the practice of care within digital health contexts, compassion as a distinct competency itself has yet to be considered in the digital realm.^{37 38} Furthermore, frameworks for digital professionalism³⁹ presently lack consideration of or guidance on how digital health technologies are to be incorporated into the practice of compassionate care, and digital contexts are often not considered in the conceptualisation of compassionate care. This divide between the discourse of digital and the discourse of compassion in healthcare is illustrated by the fact that digital health technologies are not explicitly mentioned in the Handbook of Compassion Science’s table of contents.¹³ Could it be that there is a paradox inherent in the concept of digital

compassion? Perhaps there exists a latent assumption that compassion requires an intimate, human-to-human interaction? Might compassion, therefore, be considered unachievable via and incompatible with the developing technological modalities in healthcare systems? To these authors' knowledge, how compassion is both understood and enacted within the digital realm remains unexplored terrain.

Moving forward, we need a better understanding of the intersection of compassionate care in digital contexts through considering the barriers and facilitators of technology, as well as technology's intended and unintended consequences on care delivery and healthcare interactions. Based on changing health delivery contexts and modalities, we need to identify the competencies and skills that are required for practising compassionately. This review is intended to contribute to the conversation and aid health professionals and educators in practising and teaching compassionate digital care, with the hopes to even inform software design in the future. Ensuring that compassion does not get lost within digital health is important at the level of the clinical encounter and also for the health system in whole so that we can respond to the rapidly evolving needs of patients and providers.

In reviewing the digital and compassion literature, we plan to discuss this concept from the following three perspectives: (1) from a patient–provider perspective, unique changes in styles of communication and information exchange in the context of digital care; (2) from a professional perspective, changes in required education, ethical conduct, scope of practice and practice guidelines; (3) from a systems perspective, changes in organisational policies and health professional workflows adapted to support compassionate digital healthcare.

METHODS

This protocol outlines a review that aims to define what it means to provide compassionate care in the digital sphere, that is, 'digital compassion'. We seek to inform this definition by examining the evidence-based literature on healthcare technologies. We will outline potential factors that facilitate and/or hinder compassion when health technologies are integrated into health professional workflows and patient experiences. The findings from this review will be used by AMS Healthcare whose current priority, The AMS Phoenix Project, is on compassionate care through curriculum development, adoption of standards, as well as building and supporting a community of clinical change leaders with publicly available resources.⁴⁰ Furthermore, we believe this general knowledge synthesis is a critical first step to developing conceptual and definitional frameworks for the future success of educational interventions.

This topic has not yet been addressed in the literature, to the study team's knowledge. Given this knowledge gap, we have chosen to follow Arksey and O'Malley's methodological framework for scoping reviews to allow for broad

exploration of how compassion is discussed in the digital literature as a precursor for future systematic reviews.^{41–43}

While this is not a systematic review, this protocol will also follow relevant aspects of the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols guidelines to ensure transparency and rigour in reporting the methodology.^{44 45}

To establish a baseline understanding about how compassion is operationalised when using digital technologies reported in both academic and grey literature, this review will answer the following questions:

1. How is compassion discussed in the digital health literature?
2. What are the factors that facilitate or hinder compassion as reported in the digital health literature?
3. What professional practice issues are addressed in this literature, including educational and clinical adaptations, training, pedagogical and clinical methods for providing compassionate care in a digital environment?

Search strategy

The search strategy was iteratively developed with experienced medical librarians (MA, TT) at the Toronto General Hospital in Toronto, Canada. The search strategy was first developed for Medline (table 1; table 1 legend) and then translated to query five other databases in March 2018. Since the research that is relevant to our topic is likely to be found in fields outside of medicine, we chose to search the following databases: Web of Science; ProQuest Computer Science and Computer and Information Systems Abstracts; Medline; PsycINFO; Embase; CINAHL (Cumulative Index of Nursing and Allied Health Literature). This range of databases will capture a comprehensive sample from the following disciplines: health sciences, psychiatry/psychology, social work, nursing, allied health, and computer and information systems sciences. If the search results include conference abstracts and proceedings, a subsequent search to find any corresponding follow-up articles will be conducted in Google Scholar. Finally, a 'pearl growing' also known as 'handcomb' process will also be conducted where all cited works in the included articles from the initial screening will also undergo the two-stage screening.

Both 'compassion' and 'digital' include a range of concepts/technologies and are defined in different ways in the literature of the fields in which we are interested. As a result, we are searching using index terms (subject headings) and appropriate keywords for three topics:

1. Computers, internet, smart phones, programs, applications, informatics, electronic records, e-health, telemedicine and so on AND
2. Compassion, empathy, sympathy, emotional intelligence, humanism, and so on AND
3. Communication or relationships between doctors and patients, person-centred, patient-centred, therapeutic alliance and so on.

The results from the search will be exported into the citation manager EndNote (<http://endnote.com/>),

Table 1 Search strategy for OVID Medline

#	Searches	Results
1	exp Medical Informatics/	418356
2	(digital?? or e-health or ehealth).mp.	132 134
3	exp Computer Systems/	162400
4	(info* adj4 tech*).mp.	26209
5	computer*.mp.	734409
6	(health* adj4 tech*).mp.	21 559
7	online.mp.	85504
8	(e-portal* or eportal*).mp.	15
9	(patient* adj2 portal*).mp.	4046
10	exp medical records systems, computerized/	34 754
11	(electr* adj4 (record* or medical* or health* or portal* or tech*)).mp.	145 224
12	cmc.mp.	7877
13	(telemed* or tele-consult* or tele-med* or teleconsult* or telecom* or tele-com* or telehealth or tele-health).mp.	29900
14	((virtual* or remote*) adj4 (visit* or consult* or meet* or appoint* or communicat*)).mp.	5677
15	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14	1 327 598
16	emotional intelligence/or empathy/	17802
17	(empath* or compassion* or sympath*).mp.	155 565
18	((emotion* or suffer* or illness* or unwell* or pain* or discomfort* or disabilit* or disabl*) adj4 (intelligen* or understand* or acknowledg* or consider* or recogniz* or recognition)).mp.	29584
19	(humanis* or humanit* or humane).mp.	19648
20	(dignity or dignif*).mp.	6538
21	16 or 17 or 18 or 19 or 20	207 991
22	15 and 21	9195
23	exp Communication/	272 882
24	exp Professional-Patient Relations/	133 459
25	communicat*.mp.	358 275
26	(interact* adj4 (patient* or client* or famil* or person* or professional or user*)).mp.	29 221
27	(relation* adj4 (patient* or client* or famil* or person* or professional or user*)).mp.	220 054
28	interpersonal.mp.	89 099
29	(therap* adj2 alliance*).mp.	2324
30	((person or patient* or people or human*) adj4 (centr* or center*)).mp.	97 925
31	23 or 24 or 25 or 26 or 27 or 28 or 29 or 30	864 516
32	22 and 31	1679

Continued

Table 1 Continued

#	Searches	Results
33	((artificial* or remote or virtual or tele*) adj4 (compassion* or empath* or sympath* or emotion*)).mp.	331
34	32 or 33	1998

'exp ' indicates that a subject heading is 'exploded' to include all of the narrower subject headings beneath it in the hierarchy.

'/' indicates that a term is a subject heading.

'?' holds the place of zero or one character.

'mp.' indicates that a keyword should be searched in a collection of fields including title, abstract, author assigned keywords, subject headings, etc.

'Adj4' instructs the database to search for the words before and after it within 4 words of each other in either direction (adj2 searches within 2 words of each other).

where de-duplication will be performed. This EndNote library will then be exported as a spreadsheet to use as the foundation for the screening form. Any additional results from the handcomb process will be added to EndNote and documented in a separate spreadsheet.

Study selection

Two reviewers (RC and HC or RC and LS) will independently determine the eligibility of articles using a two-stage screening process consisting of a title and abstract scan followed by a full-text review. At the end of each stage, the findings will be compared and resolved by the reviewers or a third reviewer/senior investigator (AC, GS and/or DW) when consensus is not achieved. To be relevant for full-text review, the title and abstract must:

1. Discuss use of digital technology in healthcare;
2. Discuss aspects of caring, compassionate or empathetic communication (verbal or non-verbal); and/or
3. Include patient-provider relationship (ie, therapeutic alliance, person-centred or patient-centred care/communication).

This review is inclusive of all literature published in English that is either a formative evaluation, regardless of methodology (ie, quantitative, qualitative or mixed methods, including usability studies or needs assessments), a case study or dissertation/theses. Dissertation/theses will be included to account for the maturity of literature on digital health innovations. Commentaries, editorials, letters and conference abstracts will be excluded. Additionally, seeing as our primary aim is to explore compassion towards others in clinical care, articles that primarily focused on self-compassion (eg, mindfulness-based stress reduction, compassion-focused psychotherapy) will be excluded.

Inter-rater reliability (IRR) will be established through the pilot where 20% of the Medline citations will be independently reviewed by three reviewers. From there, the IRR will be calculated and if there is an average Cohen's K of 0.70, indicating substantial agreement,⁴⁶ the remaining articles will be divided into two sets of

pairs for independent review. This way, we ensure that all reviewers cultivate a common understanding of the inclusion criteria. If the threshold is not met, then the pilot will be run again. In either instance, when comparing results, reviewers will discuss and troubleshoot any challenges experienced during the title and abstract scan.

Data collection

A standardised charting form developed by the study team will be used to extract data. The domains include article details, study details, digital technology details and compassion details. Subdomains are outlined in [table 2](#).

Prior to data extraction, this form will be piloted with three reviewers independently charting five articles, followed by validation by the senior investigators (AC, GS, DW). We will perform an iterative process where the form will be revised as needed, even during the data extraction if reviewers note and share any emerging themes not initially identified. A quality assessment will not be conducted as it is outside the scope of this review.³²

Data analysis

A narrative synthesis approach will be taken to collate, summarise and report.¹ This will include numerical summaries, using descriptive statistics, to report each high-level domain (article, study, digital technology and compassion details)⁴¹ in answering the first research question. Articles focused on the same digital technology will be grouped and treated as one unit. Subdomains in the digital technology and compassion details sections will be thematically analysed using inductive coding by three reviewers (RC, HC, LS), independently, to identify emerging themes.⁴⁷ The first 5 or 10 articles will be reviewed (depending on the number of included articles) and coded independently, after which the reviewers will discuss and formulate a coding structure. This process will be repeated so that the coding structure becomes iteratively developed as more articles are reviewed. Once all articles have been reviewed, discussed and coded, the coding structure and findings will be presented for review by the senior members of the research team (AC, GS, DW). Specifically, for the first research question, thematic analysis will be used to identify commonalities within each defined component of compassion. For the second research question, thematic analysis of the compassion details will be twofold. First, the impact of technology (barriers/hindrances and facilitators/benefits) will be categorised into the defined components of compassion as outlined by the Oxford Handbook of Compassion Science.¹³ Any other components that surface will be noted. Second, data extracted from this section will be stratified according to the Framework for Compassionate Collaborative Care,⁴⁸ which follows the Donabedian Model⁴⁹ (ie, structures, processes and outcomes). Outcomes will be stratified by the level of impact at the patient, provider or systemic level. For the final research question, thematic analysis will be conducted on the reported professional practice needs, as well as noting

Table 2 Data charting domains and subdomains

Domain	Subdomain
Article details	Article type
	Year
	Country
Study details	Study design
	Intervention (ie, educational activity, clinical intervention, simulation, etc)
	Participants
	Comparator (if any)
	Outcomes
Digital technology details	Name of technology (if available)
	Type of technology (distinguished by primary purpose)*:
	▶ Telemedicine and telehealth
	▶ Digitised medical devices
	▶ Electronic patient records
	▶ Prescribing and ordering
▶ Clinical decision support	
▶ Digital communication	
▶ Digital health games	
	Healthcare setting where technology was used (ie, mental health, primary care, surgical care, etc)
	Specific tasks accomplished through technology (eg, emailing laboratory results, tracking mood)
	Relation to verbal or non-verbal communication
Compassion details	Reported compassionate response as defined by Post <i>et al</i> (2014) ¹² †
	1. Initial recognition of suffering by an individual
	2. Emotional response to this suffering
	3. Operative response to this suffering
	Reported barriers/hindrances of technology on compassionate response‡
	Reported facilitators/benefits of technology on compassionate response‡
	Impact at which level: patient, provider and/or systemic‡
Reported professional practice needs (ie, education/training)§	

*Modified from Lupton (2014)⁵⁰ to focus on types of technologies used in patient–provider communication.

†Mapped to research question 1.

‡Mapped to research question 2.

§Mapped to research question 3.

any commonalities in theoretical constructs listed. To support this iterative process, three senior members of the research team (AC, GS, DW) as well as patients and AMS Phoenix advisory committee members will be engaged to audit decision-making, validate emerging themes and provide feedback on the results. We will retain an audit trail of each reviewer’s independent coding, team meeting notes and all variations of the coding structure.

Patient and public involvement

In addition to the senior members of the research team, patient partners and AMS Phoenix advisory committee members will be engaged to validate emerging themes and provide feedback on the results (particularly any themes that pertain to the patient–provider perspective). We will also invite these groups to contribute to the dissemination plan. Patients from the University Health Network’s ‘Patient Partners Program’ will be invited to participate in this research process. This programme falls within the network’s Patient Experience portfolio, in which they are committed to facilitating patient and caregiver contributions to important hospital planning and decision-making activities in order to provide truly compassionate, collaborative and responsive care (https://www.uhn.ca/corporate/AboutUHN/Patient_Experience/Pages/patient_partners.aspx). The AMS Phoenix advisory committee for the project ‘A Call to Caring’ consists of an interdisciplinary group of healthcare professionals who advise strategic investment to promote and sustain education and practice environments that support the balance between human compassion and technical expertise (<https://www.ams-inc.on.ca/>). By engaging these two groups, we will be following scoping review best-practices in which consumer and stakeholder involvement is encouraged to provide additional value to the study.⁴¹

ETHICS AND DISSEMINATION

This review presents the transparent and rigorous protocol that will be followed to inform and define ‘digital compassion’. Research ethics approval and consent to participate is not required for this scoping review. By synthesising the digital literature on how compassion is discussed, we will advance knowledge on compassionate care in our ever-evolving healthcare setting. This way, we may determine what the current needs are for successful compassionate professional practice in order to adapt practice and related training guidelines to include consideration of digital technologies. This knowledge synthesis is a critical first step to providing evidence-based guidance on how digital health is to be incorporated into the practice and teaching of compassionate care. These results will inform resource development and strategy for the Associated Medical Services, a Canadian Charitable Organisation at the forefront of advancing research and leadership development in health and humanities, as part of their AMS Phoenix Project: A Call to Caring. These results will also be disseminated at relevant national and international conferences, such as the eHealth, Canada’s National Conference and Tradeshow, American Medical Informatics Association (AMIA) and published in a peer-reviewed journal. We will leverage the expertise from this interdisciplinary study team to speak to the diversity of the health professions and their usage of digital health technologies as well as interdisciplinary dissemination of findings in medical education, nursing, psychiatry, psychology and informatics.

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Contributors DW led the conceptualisation, design and development of this study and protocol. RC, HC and LS drafted the protocol and helped develop the research questions. MA, an experienced medical librarian, developed the search strategy, conducted the search and copy-edited the manuscript. TT, an experienced medical librarian, copy-edited the manuscript. AC and GS provided guidance to the study conceptualisation and design, and have revised all drafts of this manuscript for content and clarity. They will also assist with the validation of the emerging themes identified in the data analysis. All authors give approval to the publishing of this protocol manuscript.

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