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Delgado-Ortiz, L. orcid.org/0000-0003-0311-7661, Polhemus, A., Keogh, A. et al. (12 more authors) (2023) Listening to the patients' voice: a conceptual framework of the walking experience. *Age and Ageing*, 52 (1). afac233. ISSN 0002-0729

<https://doi.org/10.1093/ageing/afac233>

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QUALITATIVE PAPER

Listening to the patients' voice: a conceptual framework of the walking experience

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Abstract

Background: walking is crucial for an active and healthy ageing, but the perspectives of individuals living with walking impairment are still poorly understood.

Objectives: to identify and synthesise evidence describing walking as experienced by adults living with mobility-impairing health conditions and to propose an empirical conceptual framework of walking experience.

Methods: we performed a systematic review and meta-ethnography of qualitative evidence, searching seven electronic databases for records that explored personal experiences of walking in individuals living with conditions of diverse aetiology. Conditions included Parkinson's disease, multiple sclerosis, chronic obstructive pulmonary disease, hip fracture, heart failure, frailty and sarcopenia. Data were extracted, critically appraised using the NICE quality checklist and synthesised using standardised best practices.

Results: from 2,552 unique records, 117 were eligible. Walking experience was similar across conditions and described by seven themes: (i) becoming aware of the personal walking experience, (ii) the walking experience as a link between individuals' activities and sense of self, (iii) the physical walking experience, (iv) the mental and emotional walking experience, (v) the social walking experience, (vi) the context of the walking experience and (vii) behavioural and attitudinal adaptations resulting from the walking experience. We propose a novel conceptual framework that visually represents the walking experience, informed by the interplay between these themes.

Conclusion: a multi-faceted and dynamic experience of walking was common across health conditions. Our conceptual framework of the walking experience provides a novel theoretical structure for patient-centred clinical practice, research and public health.

Keywords: walking, qualitative research, chronic condition, frailty, ageing, older people

Key Points

- By considering the voice of the patient, we defined previously unconceptualised aspects of walking and the walking experience.
- Our findings suggest that the walking experience is similar across health conditions of diverse etiology, despite specific signs and symptoms.
- Our findings support the notion that walking experience is both a complex and meaningful aspect of health for individuals living with diverse health conditions and that it is multi-faceted, dynamic and universal.
- We propose a conceptual framework of the experience of walking, which provides a novel theoretical structure for patient-centred clinical practice, research and public health.
- Future healthy ageing efforts can be built upon our framework to remain grounded in the needs and lived experiences of individuals.

Introduction

Walking is crucial for an active and healthy ageing [1, 2]. Both the rapidly ageing population and the rise of chronic and disabling health conditions worldwide [3] forecast an increase in the proportion of people living with walking impairment, as people tend to slow down and walk less with increasing age [4, 5] and in the presence of diverse health conditions [6–9]. To face this challenge, research on how to assess and modify walking and walking impairment has become a global priority [10–12]. However, for this research to be impactful, it is imperative to understand what is walking, and which aspects are meaningful to measure and modify it, specifically from the perspectives of those living with mobility-impairing health conditions.

Previous research has contributed directly or indirectly to the conceptualisation of walking, frequently framing it within the context of ageing [13–17]. Walking is generally defined as a method of locomotion which involves the use of the two legs to provide both support and propulsion [18]. However, there is consensus that walking is not an isolated activity and that it is influenced by contextual barriers and facilitators [13–17]. Thus, the International Classification of Functioning, Disability, and Health (ICF) [13], perhaps the best-known framework contributing to the conceptualisation of health constructs, formulates walking in terms of ‘body structure and function’, ‘activities and participation’ and ‘contextual factors’ [13]. These existing definitions and frameworks have made important contributions to the understanding of walking and have been frequently used in public health and research initiatives. However, they are all based on theoretical and clinical knowledge and ignore the evidence arising from personal experiences. Considered a pillar of quality in health care [19, 20], personal experiences are an important aspect of disease management,

outcome development and intervention evaluation [21–24], and they are increasingly used in decision-making processes for health priority setting [19, 20, 23]. In the case of walking, personal experiences can clarify the impact of walking impairment on people’s lives, thus suggesting priorities for future research and public health initiatives. Despite the existence of disease-specific evidence [25–30], no attempt has been made to conceptualise it in a broader manner, generalizable to diverse health conditions and usable in research of multiple conditions and in health systems’ initiatives.

This study aimed to identify and synthesise evidence describing walking as experienced by adults living with diverse health conditions and to propose an empirical conceptual framework of the walking experience. We focused on a set of pre-defined, purposively selected health conditions, representing different aetiologies (i.e. neurological, cardiopulmonary and geriatric conditions) of walking impairment, namely Parkinson’s disease (PD), multiple sclerosis (MS), chronic obstructive pulmonary disease (COPD), hip fracture, heart failure (HF), sarcopenia and frailty.

Methods

This study consisted of a systematic review of qualitative evidence and subsequent meta-ethnography (i.e. a qualitative synthesis method that is able to generate new theory from the comparison and interpretation of individual qualitative studies; Figure 1) [31–34]. Methods are reported adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses and the eMERGe meta-ethnography reporting guidance [35, 36] and are described in greater detail in the study protocol (CRD42020175038) [37] and in the Supplementary Appendices.

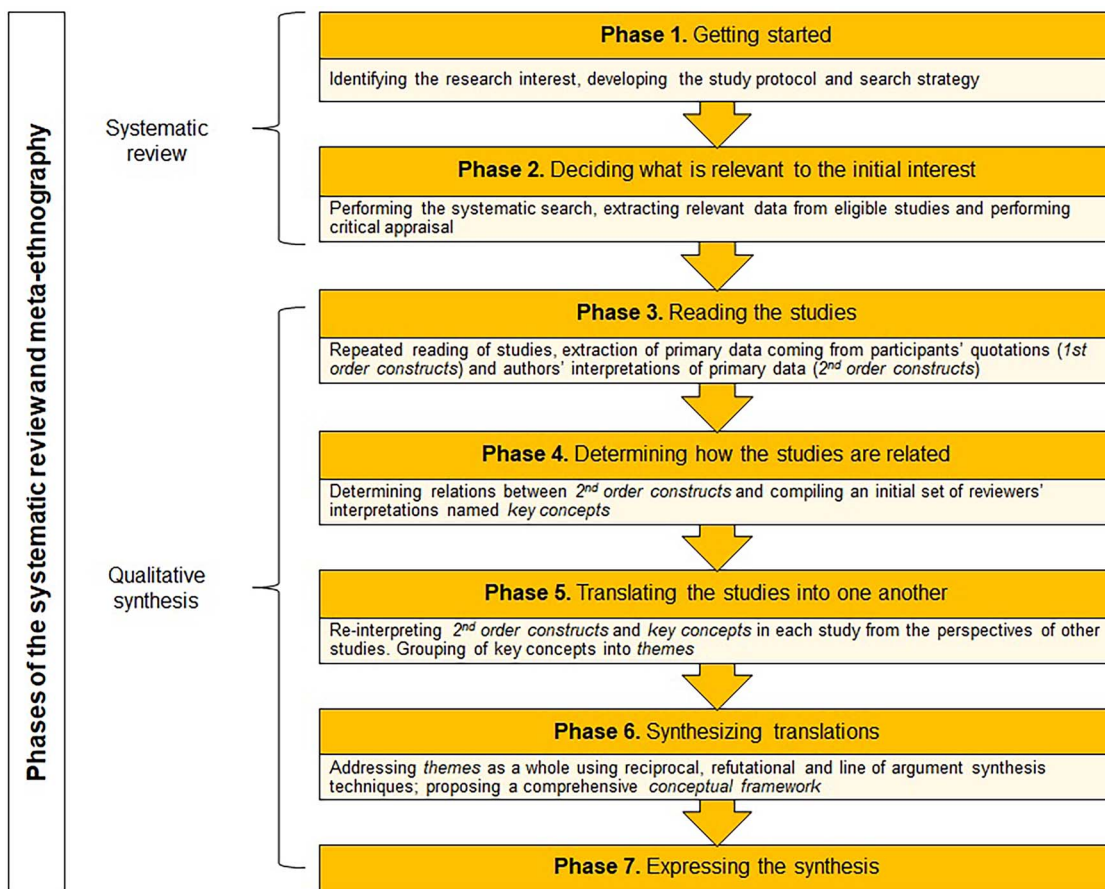


Figure 1. Phases of a systematic review and meta-ethnography.

Meta-ethnography phases 1 and 2: getting started and deciding what is relevant

We developed a systematic review search strategy in collaboration with clinical experts in geriatric medicine, neurology, pneumology and physiotherapy, epidemiologists and experts in qualitative patient experience research and an experienced research librarian. Preliminary searches demonstrated that an exhaustive review of walking impairment in all health conditions was not feasible, therefore we limited the study scope to seven highly prevalent health conditions with diverse aetiologies and impact on walking: PD, MS, COPD, hip fracture, HF, sarcopenia and frailty [11, 25–30]. We searched seven electronic databases (Medline, CINAHL, PsychINFO, Web of Science, the Cochrane Library, Embase and Scopus) from inception until March 2020 (Supplementary Appendix 1). These searches were supplemented by Google Scholar searches and manual reference screening. All peer-reviewed and grey literature were eligible, though conference abstracts were excluded. We reviewed full-text articles written in English, German, Spanish, French, Dutch, Norwegian, Hebrew, Italian, Catalan or Portuguese.

Eligible records had to address research questions related to individuals' experiences of walking in one of the included health conditions using qualitative research methods. We assessed eligibility in title, abstract and full-text

screening stages, testing for consistency between reviewers (Supplementary Appendix 2) [38]. During title and abstract screening, records passed to the subsequent stage if at least one of two independent reviewers (LD-O, AP, FK or CH) deemed them eligible. During full-text screening, two reviewers (LD-O and AP) screened all records independently, noting reasons for exclusion and solving disagreements through discussion.

One reviewer (LD-O) extracted relevant information from all studies, and another reviewer (AP) checked extractions for accuracy (Supplementary Appendix 3). Consistent with previous literature [39, 40], studies were critically appraised for their methodological quality using the NICE quality appraisal checklist [41] and were classified as acceptable or fatally flawed. Of note, methodological quality was used to classify papers but was not considered as an eligibility criterion. In addition, according to impact on our study, papers were classified as key (conceptually rich with potentially important contributions to our synthesis), satisfactory (less conceptually rich but relevant to the synthesis) or minimal impact papers (relevant but provided little content of value to the synthesis; Supplementary Appendix 4) [39]. The impact categories were used to organise and interpret studies during the synthesis process but not as eligibility criterion. During meta-ethnography

phases 3–6 (see below), we focused first on key papers; then, we used satisfactory papers to refute or validate our initial findings; and finally, we used minimal impact papers to confirm data saturation of our results. In congruence with the iterative nature of our work, we met frequently to discuss emerging perceptions, assumptions and interpretations [32] and to re-assess papers' contributions if needed.

Meta-ethnography phase 3: reading included studies

Once all eligible studies were identified, we established a synthesis team composed of three reviewers (LD-O, AP and AK) with diverse backgrounds. This team re-read included studies and individually extracted primary data coming from participants' quotations (labelled as first-order constructs) and authors' metaphors and interpretations of primary data (labelled as second-order constructs; [Supplementary Appendix 5](#)) [31, 32].

Meta-ethnography phase 4: determining how studies are related

We assessed commonalities and differences between the second-order constructs of all studies and compiled an initial set of third-order constructs (i.e. reviewers' interpretations of second-order constructs) that were named as key concepts ([Supplementary Appendices 6 and 7](#)) [32].

Meta-ethnography phase 5: translating studies into one another

In this phase, we followed a process known in meta-ethnographies as 'translation' [31–34] in which we re-interpreted the second-order constructs and key concepts in each study from the perspectives of other included studies. This re-framing allowed us to explore the nuances of each key concept, identifying similarities and differences between studies, contexts and patient populations. As the starting point of translations can influence the trajectory of the synthesis [31–34], we first grouped studies by condition and translated them within conditions following a chronological order. Then, we translated the translations from each condition into the others, with each reviewer starting from a different point. This prevented a disproportionate influence of one condition or study over the rest and forced us to actively challenge the conceptions formed during earlier phases of the synthesis. During the translation process, we grouped key concepts into a second set of third-order constructs that we named themes (i.e. reviewers' interpretations of key concepts; [Supplementary Appendix 8](#)).

Meta-ethnography phases 6 and 7: synthesizing translations and expressing the synthesis

We addressed themes as a whole using several standardised synthesis techniques (i.e. reciprocal, refutational and line

of argument synthesis) [31–34] and proposed a conceptual framework that described how walking is experienced across diverse health conditions. We invited five members of Mobilise-D Patient and Public Advisory Group [42] (two diagnosed with PD, two with MS and one with COPD) to assess the proposed conceptual framework for face validity (i.e. to discuss it within the context of their own experiences and perspectives). Where appropriate, we took their feedback into consideration to clarify or re-frame our results. Moreover, we invited two of them to critically review and co-author this publication (NS and WR).

Results

Search results

Searches identified 2,552 unique records of which 450 underwent full-text review. Ultimately, 117 studies were eligible for the meta-ethnography ([Figure 2](#)). Eligible studies represented all included conditions except for sarcopenia. Agreement among reviewers was substantial (Fleiss' $K = 0.64$ between four raters) and almost perfect (Cohen's $K = 0.98$) during abstract and full-text screening, respectively. Seventeen of the included studies were classified as key papers, 36 as satisfactory papers and 64 as minimal impact papers. With regard to methodological quality, 102 studies were considered acceptable and 15 were considered fatally flawed. Characteristics and critical appraisal of included studies are described in greater detail in [Supplementary Appendices 3 and 4](#).

Themes of the walking experience

From eligible studies, we extracted the first- and second-order constructs and subsequently identified 32 key concepts describing different aspects of the walking experience ([Supplementary Appendixes 6 and 7](#)). These key concepts were common to all conditions and therefore were grouped into seven inter-related themes that explain the experience of walking in the presence of diverse health conditions ([Supplementary Appendix 8](#)). Themes were identified in all included conditions and are described as in the following text.

Becoming aware of the personal walking experience

We consistently identified that, in the presence of signs and symptoms of mobility-impairing health conditions, walking deteriorates and begins to require conscious effort, resulting in an awareness of walking which is not present when walking is unimpaired. From the moment (or moments) in which changes in walking are noticed, individuals become increasingly aware of their need to increase physical exertion, concentrate, plan ahead and adapt to complex environments. From then on, they realise the integral role of walking in their daily activities and often compare their current experiences to an effortless past in which walking was perceived as easy and automatic ([Supplementary Appendix 8](#)).

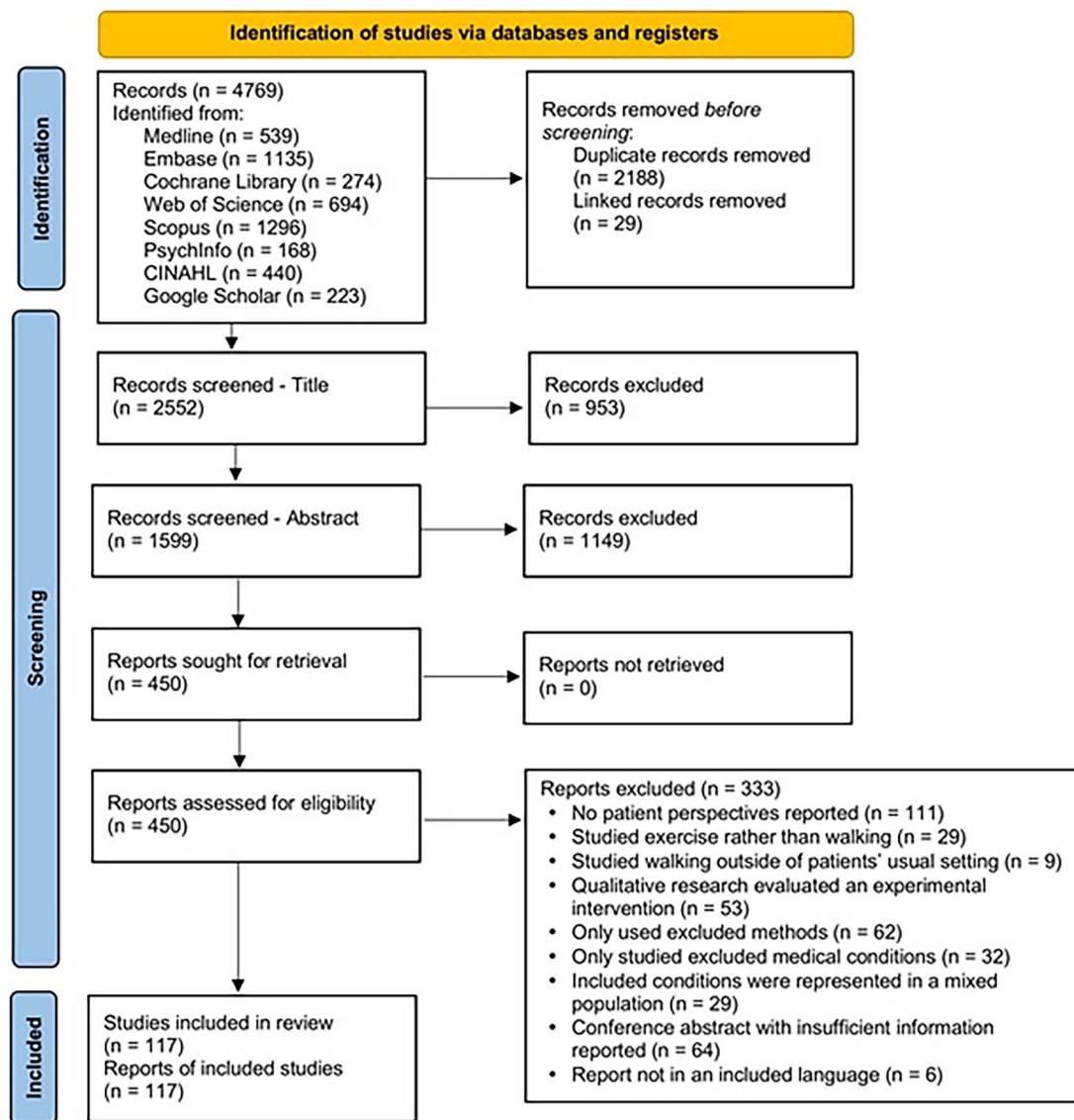


Figure 2. Flow diagram of included studies.

The walking experience as a link between individuals' activities and sense of self

The walking experience relates to individuals' desire to perform activities which could potentially be hampered by impairment. These walking-related activities of daily living may be basic (such as bathing or dressing), instrumental (such as performing household chores or grocery shopping), leisurely (such as engaging in a hobby or dog walking) or work-related. Experiences reflect both the ability to perform these activities as well as the walking-related adverse events experienced during these activities, such as falls or symptom exacerbations. Walking is symbolic of independence, control, normalcy and well-being because it governs one's ability to engage in activities safely. When walking impairments affect activities associated with domestic and social roles, they indirectly challenge individuals' sense of self. Thus, individuals' sense of self is inextricably linked to

the walking-related activity through the walking experience (Supplementary Appendix 8).

The physical walking experience

Individuals consistently described a physical experience of walking, which is characterised by an overall loss of physical function. Common signs and symptoms of each condition affect—or are affected by—walking performance both directly and indirectly. Many of these signs and symptoms are common across conditions, including fatigue, pain, weakness and lack of balance. Changes to walking performance, such as slowed walking speed, altered step patterns and reduced ability to take long walks, are also common. Unpredictable symptoms cause walking ability and walking experiences to vary from day to day and even hour to hour. Walking impairments also raise notable physical safety risks associated with falling, exacerbation

or becoming stranded when the walking ability suddenly changes (Supplementary Appendix 8).

The mental and emotional walking experience

Across all conditions, individuals describe walking as a complex mental and emotional experience. Initial experiences of mourning and loss are almost universal as individuals become aware of their walking impairments. Thereafter, walking is often accompanied by feelings of fear, anxiety, stress, anger, frustration and embarrassment during or in anticipation of walking activities. Fear and anxiety often cause withdrawal and reduced participation, resulting in feelings of loneliness and hopelessness. As walking becomes increasingly effortful, additional motivation is required to initiate and complete activities, though the desire to maintain fitness or health increases motivation to walk. In this context, walking-related activities are frequently framed as goals that, when successfully completed, lead to positive feelings of satisfaction, fulfilment and achievement (Supplementary Appendix 8).

The social walking experience

Individuals describe a social experience of walking which can be enhanced or hindered by walking impairments. Individuals' social networks influence walking experiences at home, at work and in the broader community and therefore moderate the ability to sustain participation in daily life. Individuals assume different roles and identities within these networks, which are typically influenced by social and gender norms and frequently threatened by walking impairment. The availability of social support often influences individuals' engagement in activities which require walking, with lack of support leading to withdrawal, decreased participation and social isolation. Supportive networks accommodate walking impairments and foster a sense of belonging, whereas unsupportive networks prompt a sense of otherness when unwanted visible impairments lead to social judgement or misconceptions (Supplementary Appendix 8).

The context of the walking experience

Physical, mental and emotional and social experiences of walking are framed within physical, social-cultural and personal contexts. Physical contexts include indoor and outdoor environments in individuals' life spaces. The home is perceived both as a safe, familiar space and as a challenging space where falls often occur and obstacles are difficult to navigate. Neighbourhoods and communal spaces challenge individuals with uneven surfaces and crowds, demanding extra attention and often triggering additional walking difficulties. At the community level, walking impairments limit individuals' ability to use powered transportation such as buses. Furthermore, weather and climate often make walking more dangerous or difficult. The socio-cultural context includes social and cultural norms, which determine whether individuals engage in certain walking-related activities or

not. Individuals often compare themselves to others to assess and contextualise their own level of walking impairment. Finally, the personal context includes personal attitudes, past experiences, ageing, the presence of comorbidities and other characteristics that could impact the walking experience (Supplementary Appendix 8).

Behavioural and attitudinal adaptations resulting from the walking experience

Walking experiences frequently prompt attitudinal and behavioural responses, many of which entail strategies for coping with the effects of walking impairment. Some strategies, such as engaging in structured exercise or participating in interventions, aim to maintain function. Others aim to manage changing abilities through staying positive, planning ahead, pacing or adopting assistive technologies. Many of these strategies, especially the adoption of assistive technologies, carry a psychological toll as individuals grapple with their changing abilities and identities. In many cases, individuals are forced to prioritise among activities that are considered of high value and may ultimately choose to forego activities that become too dangerous, difficult or psychologically daunting. Changes in behaviour often reflect attitudinal changes towards walking-related activities, physical activity, social priorities and the future (Supplementary Appendix 8).

Conceptual framework describing walking as experienced in the presence of chronic conditions

Using the seven identified themes, we developed a conceptual framework that visually represents the experience of walking for individuals living with health conditions which impair walking (Figure 3). Briefly, walking experience is multi-faceted, with constant interplay between its physical, emotional and social components. Walking experience is framed by the context (physical, socio-cultural and/or personal) and the activities individuals aim to perform. Moreover, the walking experience creates a link between daily activities and the sense of self as changing abilities shape social roles, attitudes and behaviours over time.

Discussion

In this systematic review and meta-ethnography, we synthesised 117 qualitative research studies addressing the walking experience from the perspective of individuals living with diverse health conditions. We found that the experience of walking is: (i) multi-faceted, as it is composed by seven inter-related themes; (ii) similar across conditions of diverse aetiologies and (iii) dynamic, as the walking experience is constantly modifying and modified by the context, the specific activities and the individual's behaviour and sense of self. Based on these findings, we propose a novel framework to describe walking, informed by the experiences of individuals living with diverse health conditions.

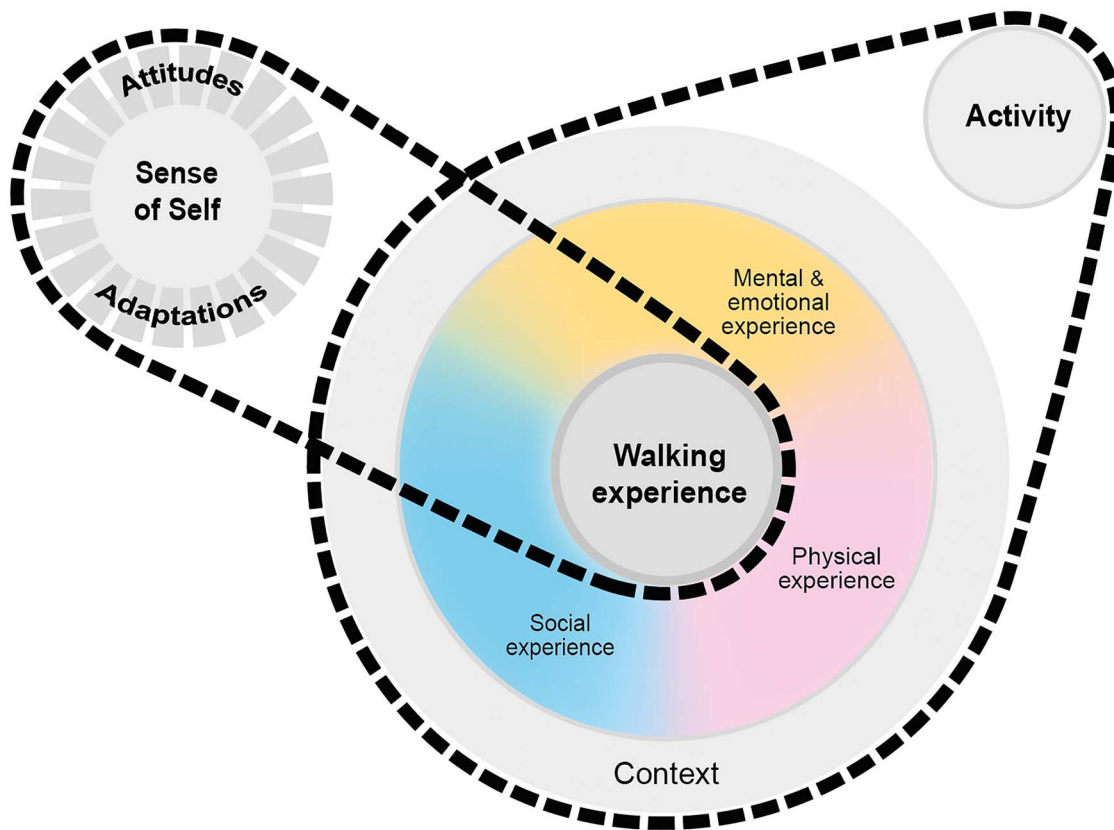


Figure 3. Conceptual framework describing walking as experienced in the presence of diverse health conditions. The framework uses the metaphor of a mechanical system to explain how people experience walking from the moment they become aware of it. Physical, social and mental walking experiences are framed by context and the activity at hand. These experiences link an individual’s walking-related activities to their sense of self through behavioural and attitudinal adaptations. Reflexively, the individual’s newly revised sense of self, behaviours and attitudes affect future experiences and participation in walking-related activities.

Main results and comparison with previous research

We identified the experience of walking as a multi-faceted concept, supporting and advancing previous conceptualisations of walking. The aspects of our framework related to activities, physical and social experiences, and adaptations align with the concepts ‘body structure and function’ and ‘activities and participation’ of the ICF model [13]. Similarly, context and adaptations are consistent with previous frameworks considering these factors as part of walking [13–17]. Importantly, our study identified themes that were not addressed by previous conceptualisations, such as the awareness, sense of self, mental experience and attitudes. These themes were closely interrelated with, but distinct from, previously identified concepts. By considering the voice of the patient, we defined previously unconceptualised aspects of walking which are meaningful to individuals, thus contributing directly into one of the four action areas of the United Nations’ Decade of Healthy Ageing (2021–2030) [1].

A surprising finding of this meta-ethnography is that walking experiences are similar across health conditions despite diverse signs and symptoms. This finding challenges traditional disease-focused and function-centric

perspectives which interpret walking impairments in terms of a condition’s hallmark symptoms. Our results show that walking should be assessed not only according to clinical milestones but also according to its personal meaning and impact [24]. This reflection resembles early discussions on integrated care when the care for patients with chronic or disabling health conditions faced problems of fragmentation, incoordination, discontinuity across time, place and discipline [43–47]. By assuming the patient-centred perspective of integrated care also in the walking field [43, 46], walking impairments remain disease-specific, but walking experience becomes a universal concept.

Our conceptual framework suggests a dynamic mechanism by which the physical, mental and social experiences of walking constantly change, modify and are modified by the performance of walking-related activities and by the individual’s sense of self. At the same time and in response to walking experiences, individuals are constantly changing their attitudes and adapting their behaviour. As an example, an individual who can no longer go grocery shopping independently (activities and sense of self) due to a disabling health condition may decide to start using a cane regularly (adaptations) which changes their physical, mental and social

experiences of walking. This dynamic nature of the walking experience aligns with established theories describing the impact of health conditions on life experiences, such as normalisation (i.e. constant adaptation to a 'new normal') [48] or the shifting perspectives model [49]. Thus, our framework of walking experience suggests that repeated walking assessments should complement current clinical assessments of disabling health conditions to enable appropriate and meaningful health care.

Clinical relevance

Our findings confirm that walking is a meaningful aspect of health which should be addressed in regular clinical practice even when it is only indirectly affected by a condition's underlying aetiology. As key providers of healthcare treatments and advice, clinicians are encouraged to: (i) assess walking experience regularly and repeatedly as a multi-faceted vital sign, since this will provide them with useful information on how they can help patients meet their long term care needs, improve their quality of life and maintain independence at older ages. Assessment may include a conversation with patients to ask about how they perceive and experience changes in their everyday walking (i.e. how this affects their ability to carry out their daily routine activities such as going to the shops, crossing the road and any other personal, social and work-related challenges they experience). It may also include the perceptions of carers/partners or other family members where possible, and it may also consider formal tools to assess patients' perception and capacity of walking and if this has changed; (ii) provide adequate and targeted walking advice to patients according to their individual physical, mental and social conditions and needs, and (iii) eventually refer them to allied professionals to prompt secondary or tertiary prevention strategies [50] that also take into consideration the walking-related activities patients want to perform, the context in which they walk and the changes in their attitudes and adaptations to the presence of walking impairment.

Implications

This study provides a novel theoretical structure for future work in the context of an active and healthy ageing [1, 2, 51], and therefore it also has important implications for research and public health. First, future research should complement current methods for measuring walking, which predominantly reflect mechanics and lower limb function, with innovative tools which reflect the lived experience of walking [11, 12, 52]. These tools should capture aspects of the walking experience which are meaningful to individuals [12, 24] and, once validated, should be used as outcome measures in drug and non-drug therapeutic and preventive trials as well as in observational studies to describe levels, correlates and changes over time in walking experience [12, 52]. As an example, the recently developed and validated PROactive Physical Activity (PPAC) suite of instruments in COPD measure patients' experience of physical activity

[53, 54] and have provided both better characterisation of physical activity [55] and a deeper understanding of the effectiveness of drug interventions [56, 57] than objectively measured physical activity. Second, our results contribute to current healthy ageing international efforts by establishing a detailed list of interrelated themes and a conceptual framework upon which new public health interventions and care delivery modes can be built [1].

Strengths and limitations

Our study has some limitations. First, we considered evidence arising from six chronic conditions with variable levels of evidence. To avoid bias or the undue influence of a single condition, these six were chosen carefully to reflect diversity, and evidence was considered through a thorough, standardised synthesis process. Still, the generalizability of our framework to other health conditions, such as rheumatic diseases, should be confirmed. Second, by excluding studies written in languages unfamiliar to the review team, we might have missed evidence arising from different socio-cultural contexts. Third, we considered evidence available until March 2020 and it is possible that potentially relevant studies have been published since then. However, taking into consideration that we reached conceptual saturation during the synthesis process [58], the inclusion of more recent studies would likely yield similar results.

Our review also has several strengths. First, we ensured methodological rigour by strictly adhering to appropriate guidance for synthesizing qualitative evidence [35, 36]. Second, the review and synthesis teams included researchers from diverse personal and professional backgrounds. This diversity fostered discussion and challenged each member to evaluate studies from multiple perspectives. Third, we considered the theoretical and methodological contexts of individual studies while discussing our findings and interpretations. Finally, we assessed the validity of our synthesis and conceptual framework through member checking with individuals living with the health conditions under study.

Conclusion

We found that a multi-faceted and dynamic experience of walking is common across mobility-impairing health conditions and proposed a conceptual framework of the walking experience which provides a novel theoretical structure for patient-centred clinical practice, research and public health.

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

Acknowledgements: This work was supported by the Mobilise-D project that has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No. 820820. This JU receives support from the European Union's Horizon 2020 research and innovation programme and the European Federation of

Pharmaceutical Industries and Associations (EFPIA). Content in this publication reflects the authors' view and neither IMI nor the European Union, EFPIA or any associated partners are responsible for any use that may be made of the information contained herein. ISGlobal acknowledges support from the Spanish Ministry of Science, Innovation, and Universities through the 'Centro de Excelencia Severo Ochoa 2019–2023' Programme (CEX2018-000806-S) and support from the Generalitat de Catalunya through the CERCA Programme.

Declaration of Conflicts of Interest: W.M. receives or received funding from the European Union, the German Federal Ministry of Education of Research, Michael J. Fox Foundation, Robert Bosch Foundation, Neuroalliance, Lundbeck and Janssen. He received speaker honoraria from Abbvie, Bayer, GlaxoSmithKline, Licher MT, Rölke Pharma and UCB and was invited to Advisory Boards of Abbvie, Biogen, Lundbeck and Market Access & Pricing Strategy GmbH and is an advisory board member of the Critical Path for Parkinson's Consortium. He serves as the co-chair of the MDS Technology Task Force. L.R. is supported by the National Institute for Health Research Newcastle Biomedical Research Centre (BRC) based at Newcastle upon Tyne Hospital NHS Foundation Trust and Newcastle University. B.S. is supported by the Sheffield BRC based at the Sheffield Teaching Hospital and the University of Sheffield. The remaining authors declare no competing interests.

Declaration of Sources of Funding: This work was supported by Mobilise-D, a European project that has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No. 820820. The funder did not play a role in the study design, data collection, analysis, interpretation of data, writing of the report or in the decision to submit the paper for publication.

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Received 8 April 2022; editorial decision 1 August 2022