

THE INDEX OF CARE

An open-access, cloud application for bioarchaeology of care research

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INTRODUCTION

BIOARCHAEOLOGY OF CARE research identifies and analyses evidence for disability and health-related care in the past, and is case study-based, contextualised and cross-disciplinary. Triggered by physical indicators in human remains suggesting a period of survival with severe and/or functionally-limiting pathology, the methodology comprises four sequential stages of analysis which progress from description, through inference, to interpretation:

- Stage 1** - compiles information about the subject, their pathology, and their lifeways;
- Stage 2** - assesses likely disability impact and establishes whether care was likely required;
- Stage 3** - derives a broad 'model of care' likely provided; and
- Stage 4** - explores the broader implications of this care for group and individual agency and identity.

In any culture the decision to give care, the decision to accept care, and the form this care takes can provide a window into the values, beliefs, knowledge, skills and social and economic organisation of all involved (whether directly or indirectly). The bioarchaeology of care looks at aspects of the lives and lifeways of those who cared, and those who were cared for, which might otherwise remain invisible¹.

The **INDEX OF CARE** (www.indexofcare.org) is an on-line instrument for assisting researchers to 'think through' a bioarchaeology of care study². Linked worksheets prompt consideration of relevant biological and archaeological variables; operationalise key concepts such as 'disability', 'care' and 'agency'; facilitate ordering and analysis of evidence; and help in achieving rigour and transparency throughout the research process. We may think we know what constituted a disability* requiring care in the past, but it can be easy to underestimate a person's ability to cope with the effects of disease; wherever relevant, the Index urges utmost caution in assessment and interpretation.

The Index contains four 'steps' corresponding to the bioarchaeology of care 'stages', and all provide the rationale for the material they cover. The Index is non-prescriptive: most items are open-ended; most information sought is qualitative; most input is in text format; and speculation is encouraged. Published in 2014, the Index has already been employed in many bioarchaeology of care studies³.

Version 2 of the Index of Care, incorporating user feedback and with expanded data collection options, will be available at the end of 2018.

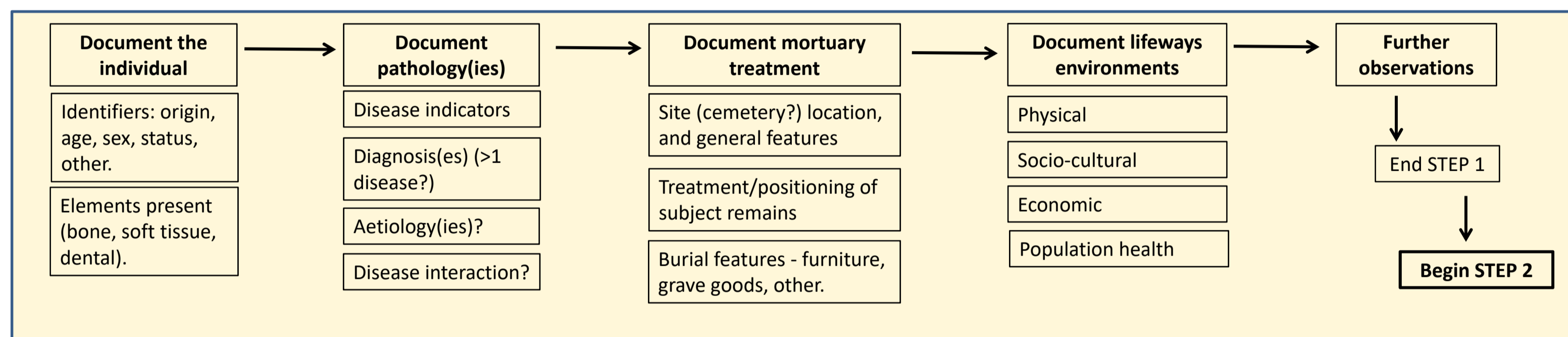
* 'Disability' is an umbrella term covering impairments, activity limitations and participation restrictions, given meaning by the specific context in which it occurs (World Health Organisation, 2011)

THE FOUR STEPS OF THE INDEX OF CARE

STEP 1:

Describe, diagnose, document

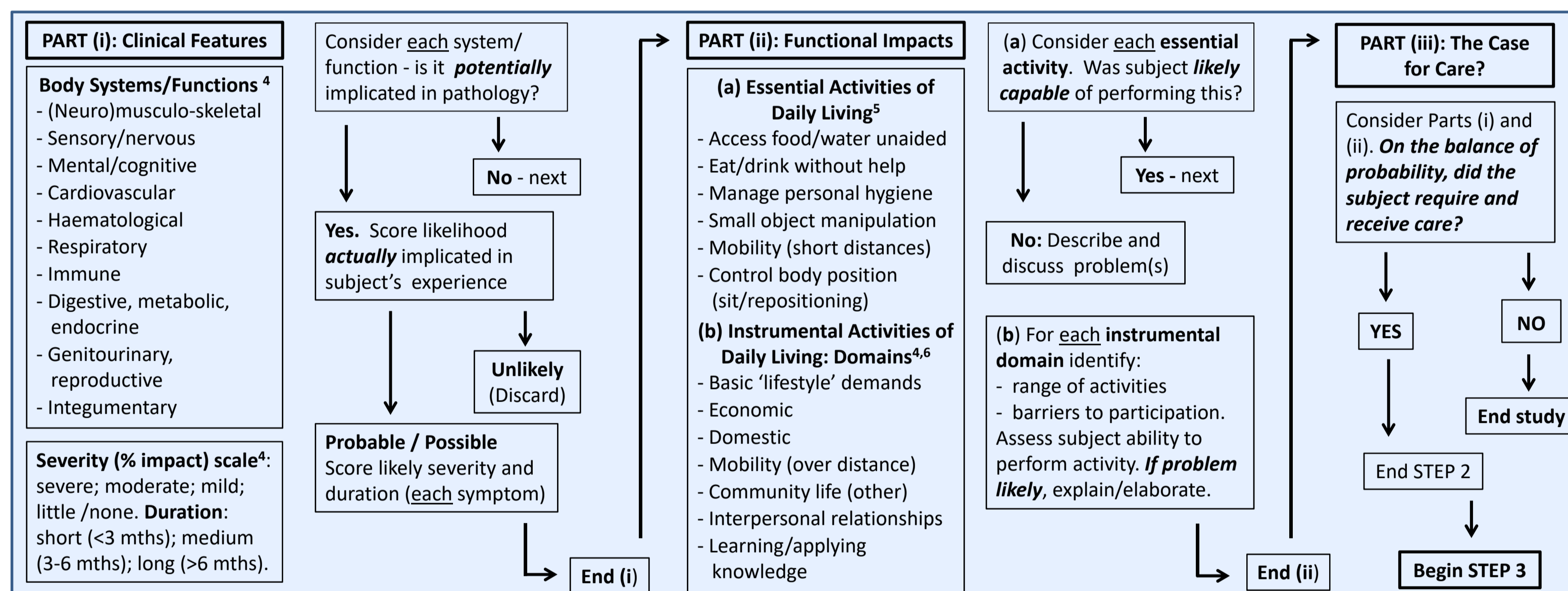
Gathers all individual and archaeological (lifeways) information available and relevant to the subject, providing the context - *the foundation* - essential for all analysis and interpretation in Steps 2-4.



STEP 2:

Assess disability/need for care

Made up of **three parts**: (i) considers likely **clinical** features of the subject's pathology; (ii) based on (i), and within the parameters of lifeways context [Step 1], identifies likely **functional** impacts in terms of (a) *Essential activities of daily living* and/or (b) *Instrumental activities of daily living*; and (iii) asks whether, based on (i) and (ii), care was most likely required and received. If 'YES', the study continues [Step 3]; if 'NO', the study ends.

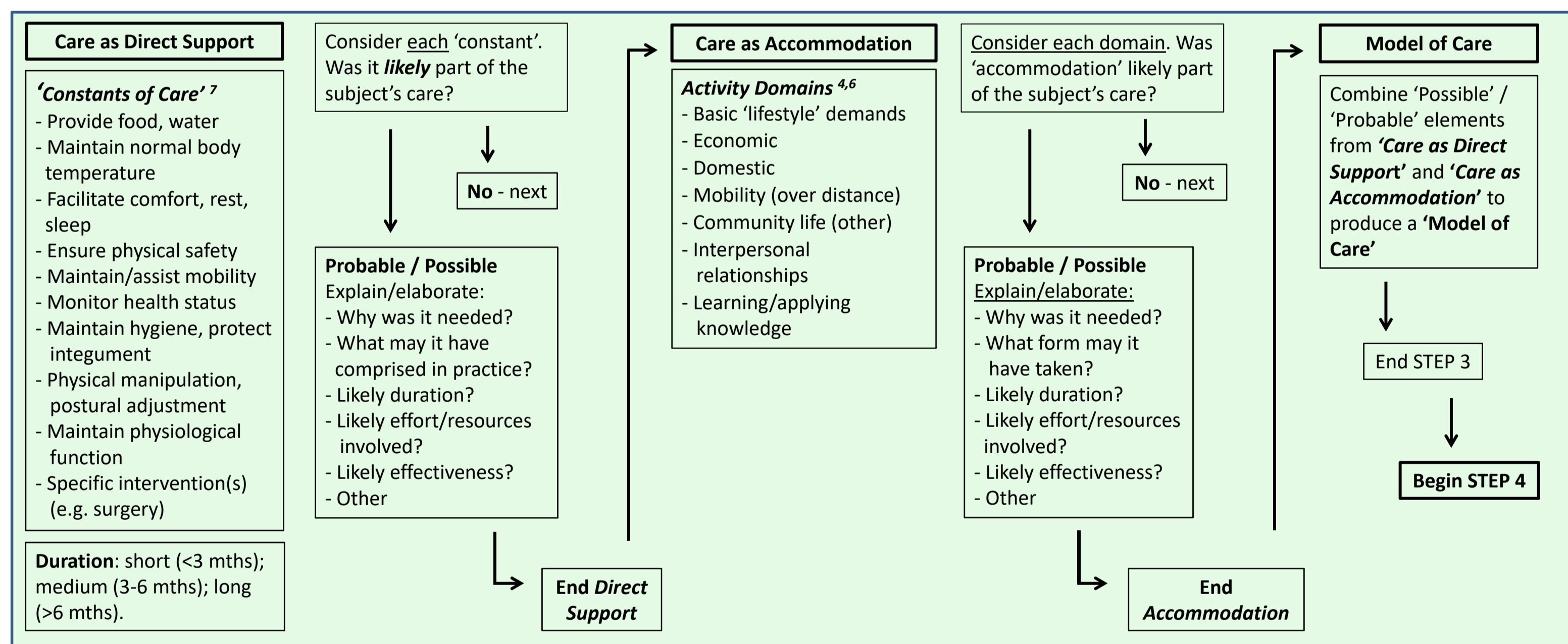


STEP 3:

Construct a model of care

Produces a model of likely care provided in response to clinical and functional impacts [Step 2] within the constraints of lifeways [Step 1]. Model covers e.g. basic elements of care*; care duration; skills and resources required and available; 'costs'. 'Caregiving' is conceptualised along a continuum between 'direct support' ('hands-on') to 'accommodation' (group adjustments to achieve subject inclusion).

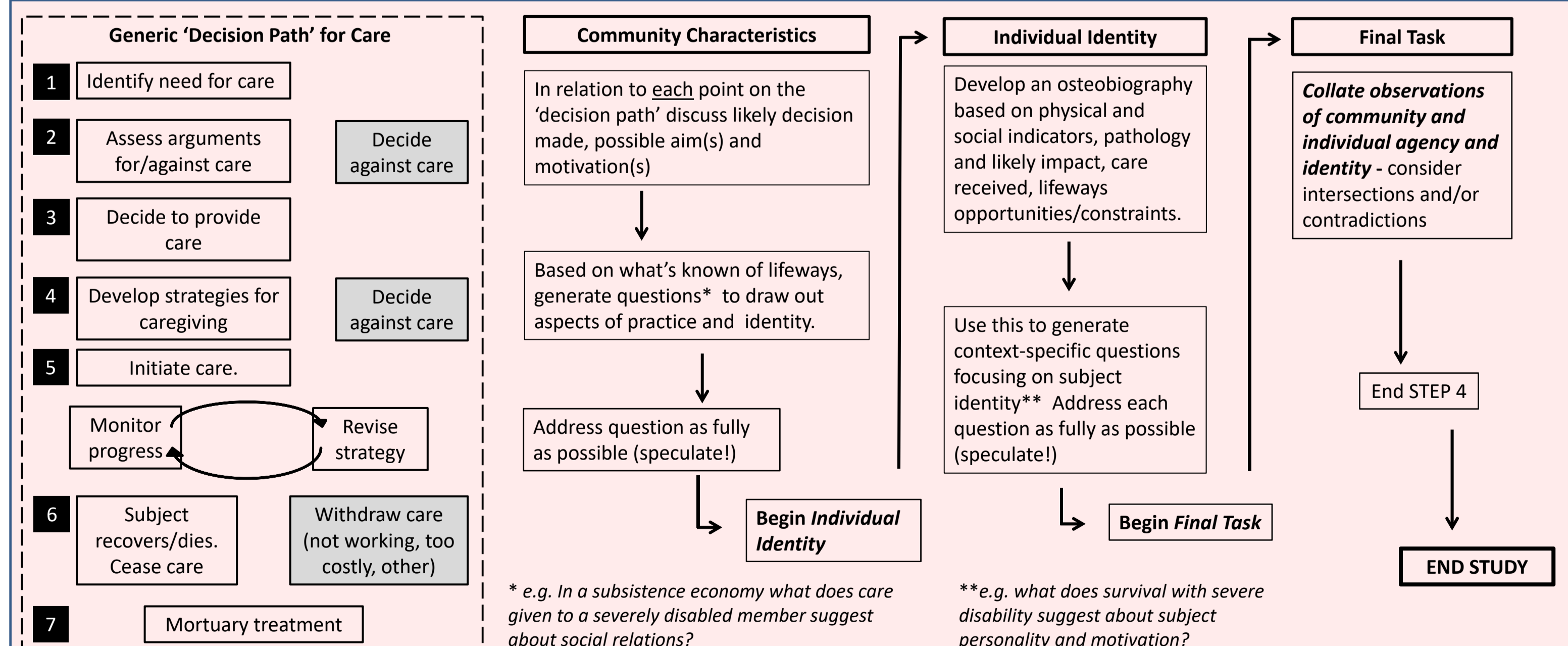
* *Fine detail is inaccessible, but a 'constant' human physiology allows us to presume certain 'constants of care' in response to particular disease symptoms.*



STEP 4:

Interpret implications of care

Unpacks implications of care given [Step 3] for understanding aspects of community social relations, practice and organisation, and subject identity. Giving *and* receiving care always involves choice - and so reflects agency. The Index posits a generic decision pathway for care, asking users to speculate about what underlies choices made at each point and what these suggest about the society. It then uses an osteobiography of the subject to examine what experience of disability and care may suggest about the subject as a *person*.



A FINAL WORD ...

The **Index of Care** does *not* contain a formula for analysing disability and care - it does *not* pretend to generate 'answers'. Just as every individual's experience of disease is unique, so is every case study of their care; if answers *are* available, it is up to the researcher to find them. The Index is a tool to help in this process. There are no restrictions imposed on its application; researchers may choose to use some Steps or worksheets but not others, or may simply use worksheets to remind themselves of issues worth considering. The Index of Care is intended to be flexible - to meet users' needs and to be employed only to the extent that users are comfortable with content and direction.

EXAMPLE 1: Man Bac Burial 9⁸



DESCRIBE ~4000 BP; male, ~20-25 yrs., North Vietnam. ~75% complete. C1-T3 fused, extreme bone atrophy, fused sacro-iliac joint, no evidence trauma or infection. **Pathology**: quadriplegia (acquired ~12-14yrs, complication congenital Klippel-Feil Syndrome). **Mortuary**: cemetery, flexed N-S (standard supine E-W), 2 pots. **Lifeways**: sedentary, small group, hunter-gatherer (fishing), estuarine environment.

ASSESS NEED FOR CARE **Clinical**: **Certain** - upper (partial) and lower (complete) body paralysis; torticollis; osteoporosis. **Probable** - depressed immune system; cardiovascular, gastrointestinal, and respiratory dysfunction; kidney failure; pressure sores. **Possible** - pain; depression. **Functional**: Immobile - incapable of all 'Essential activities of daily living' and of all physically demanding 'Instrumental activities of daily living'. Lived ~10 yrs with quadriplegia. **Care Needed?** YES

MODEL OF CARE **Direct support**: all 'constants of care' - continuing and intensive nursing, including regular monitoring of health status, hygiene (waste removal, bathing, protect integument), feeding (special diet?), maintain hydration and temperature regulation, massage and positioning (encourage organ function, prevent pressure sores). **Accommodation**: likely included effort to involve in social activity (important psychological requirement).

INTERPRET **Community**: long-term survival and absence of infection/fracture reflect skilled, labour-intensive care; community cooperation and flexibility in managing 'costs' of, and organising around, care; non-fatalist philosophy - 'cure' impossible but care given (suggests value placed on all group members?); 'deviant' burial - inclusion, but also acknowledges/respects difference? **Individual**: strong will to live; adaptable; socially engaged; strong self-esteem.

EXAMPLE 2: Romito 2⁹

DESCRIBE ~11,500 BP; male, 17-20 yrs, ~110 cms, Calabria, Italy. ~75% complete (not all bones in image). Limbs disproportionate; forearm, wrist, hand, foot, cranial anomalies; spinal pathology. **Pathology**: very rare dwarfism (acromesomelic dysplasia). **Mortuary**: double burial with female, supine N-S, 2 auroch horns. **Lifeways**: small group; hunter-gatherer (meat diet); mobile; mountainous terrain; frequent nutritional stress.



ASSESS NEED FOR CARE **Clinical**: **Certain** - dwarfism; limited forearm extension (130°); restricted forearm pronation, supination; hand and foot bone deformities. **Probable** - developmental delays in infancy; poor mobility and

endurance; reduced grip/manipulation skills. **Possible** - neuropathic pain; endocrine, respiratory, cardiovascular complications. **Functional**: independent in all 'Essential activities of daily living', but restricted in 'Instrumental activities of daily living'. Limited mobility and manipulation skills mean *not* able to participate in primary economic activity (hunting) nor work in bone, stone, wood; problems in keeping up over challenging terrain. **Care Needed?** YES*
* *In this study, context is particularly important in assessing need for care.*

MODEL OF CARE **Direct support**: likely not required. **Accommodation**: extended nurturing in early childhood to compensate for developmental delays. Following this, acceptance of/adjustment to differences in subject's physical functioning, revising normative expectations of (male) group member. Dietary and burial evidence indicates full social inclusion - possible adoption of alternative strategies for subject participation (e.g. foraging for plants, firewood)?

INTERPRET **Community**: in a small, subsistence group, maintaining someone unable to contribute 'equally' suggests strong internal cohesion, and willingness and ability to juggle task allocation/scarc resources. Unlikely dwarfism known previously, so 'acceptance of difference' suggests social and cognitive flexibility and/or a 'dividual society' (i.e. all group members are part of indivisible whole, with individual differences secondary). **Individual**: living with constant physical challenges in harsh lifeways suggests resilience.

REFERENCES

1. Tilley, L. 2015a. *Theory and Practice in the Bioarchaeology of Care*. New York: Springer.
2. Tilley, L. and Cameron, T. 2014. Introducing the Index of Care. *International Journal of Paleopathology* 6:5-9.
3. For example, see chapters in Tilley, L. and Schrenck, A.A., Eds. 2017. *New Developments in the Bioarchaeology of Care*. New York: Springer.
4. Boutin, A.T., 2016. Exploring the social construction of disability: An application of the bioarchaeology of personhood model to a pathological skeleton from ancient Bahrain. *International Journal of Paleopathology*, 12:17-28. Dongoske, K.E. et al. 2015. Bioarchaeology of Care: A Hohokam Example. *Int. J. Paleopathol.* 22:214-223. Viala, M. et al. 2017. A new application of the bioarchaeology of care approach: a case study from the Metal Period, the Philippines. *International Journal of Osteoarchaeology* 27:662-671.
5. Adapted from Katz, S. et al. 1970. Progress in development of the index of ADL. *The Gerontologist* 10:20-30.
6. Adapted from Australian Department of Veterans' Affairs. 1998. *Guide to the Assessment of Rates of Veterans' Pensions*. Canberra: Commonwealth of Australia.
7. Adapted from Henderson, V. 1966. *The Nature of Nursing*. New York: Macmillan.
8. Tilley, L. and Oxenham, M.F. 2011. Survival against the odds: modeling the social implications of care provision to a seriously disabled individual. *International Journal of Paleopathology* 1:35-42.
9. Tilley, L. 2015b. Accommodating difference in the prehistoric past: Revisiting the case of Romito 2 from a bioarchaeology of care perspective. *International Journal of Paleopathology* 8:64-74.

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