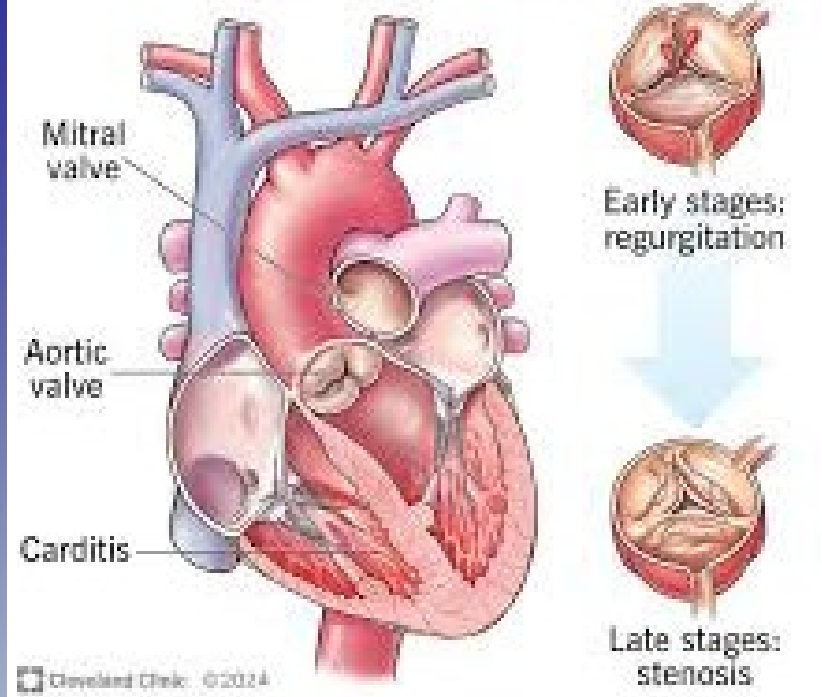

Acute Rheumatic Fever (ARF)and Rheumatic Heart Disease (RHD): Lessons from Coroners' Inquests

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See I Freckelton, "Acute Rheumatic Fever & Rheumatic Heart Disease: Health Insights from Coroners' Inquests" (2025) 31 Journal of Law & Medicine 653

Acknowledgment of Country

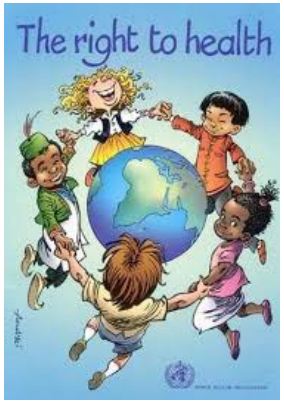
- I acknowledge the traditional custodians of the unceded lands on which this talk is being delivered, past, present and emerging, and on which all participants in this gathering are residing and visiting.
- In particular, I acknowledge the hospitality of the Arrernte Nation of Alice Springs and of the Warlpiri People of Yuendumu with whom I have been working and living for much of the last two years, and the loss they have suffered with the deaths of Kumanjayi Walker and Kumanjayi White.

Aspirations for the Talk

- To explore an important intersection between medicine and law
- To incorporate a focus on coronial inquests which can be overlooked as a source of insight on threats to health
- To employ a public health law lens
- To reflect on what the right to health means as a matter of law
- To shine a light on an uncomfortable aspect of contemporary life and health services for Australia's Indigenous community

Right to Health

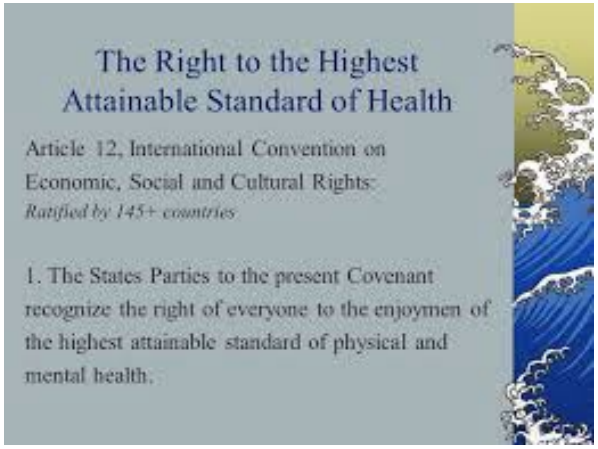
- Confusingly expressed notion, not known to international or domestic law
- Preferable: The right to the highest attainable standard of health



ICESR, 1976, Article 12

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

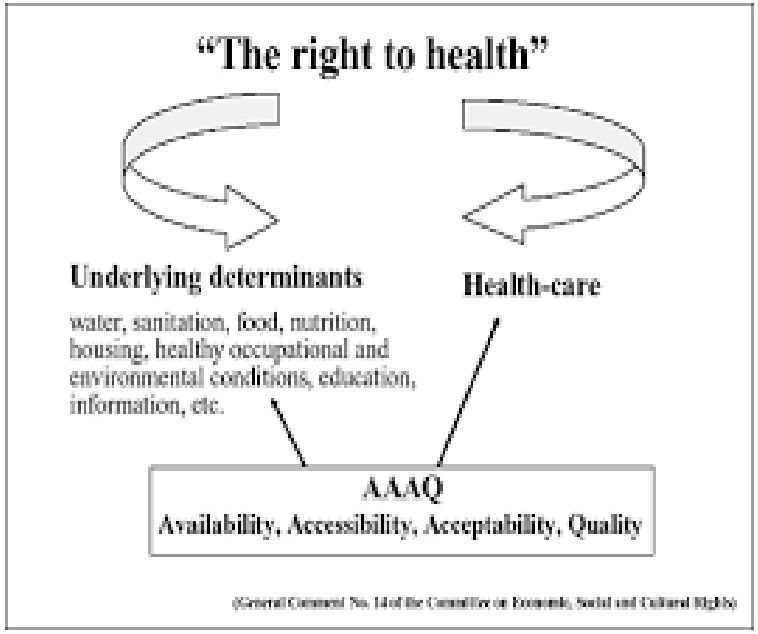
- 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
- (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
- (b) The improvement of all aspects of environmental and industrial hygiene;
- (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases
- (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.



General Comment No 14

Committee on Economic, Social and Cultural Rights interpreting Art 12 in General Comment 14:

- Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity. The realization of the right to health may be pursued through numerous, complementary approaches, such as the formulation of health policies, or the implementation of health programmes developed by the World Health Organization (WHO), or the adoption of specific legal instruments. Moreover, the right to health includes certain components which are legally enforceable.



General Comment No 14

- The right to health is not to be understood as a right to be healthy. The right to health contains both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.

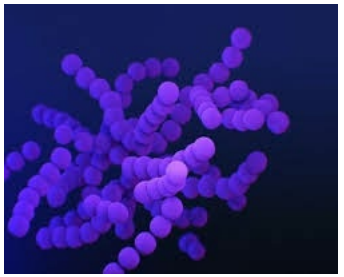
General Comment No 14

- Indicia by reference to which states' fulfilment of citizens' right to health can be evaluated:
  - Functioning public health and health-care facilities, goods and services, and programmes should be available in sufficient quality ("Availability")
  - Health facilities, goods and services should be accessible to everyone without discrimination. This entails physical and economic accessibility as well as "information accessibility" the right to seek, receive and impart information and ideas concerning health issues ("Accessibility)"
  - All health facilities, goods and services should be respectful of medical ethics and be culturally appropriate ("Acceptability")
  - Health facilities, goods and services should be scientifically and medically appropriate and of good quality, this requiring, amongst other things, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation ("Quality")

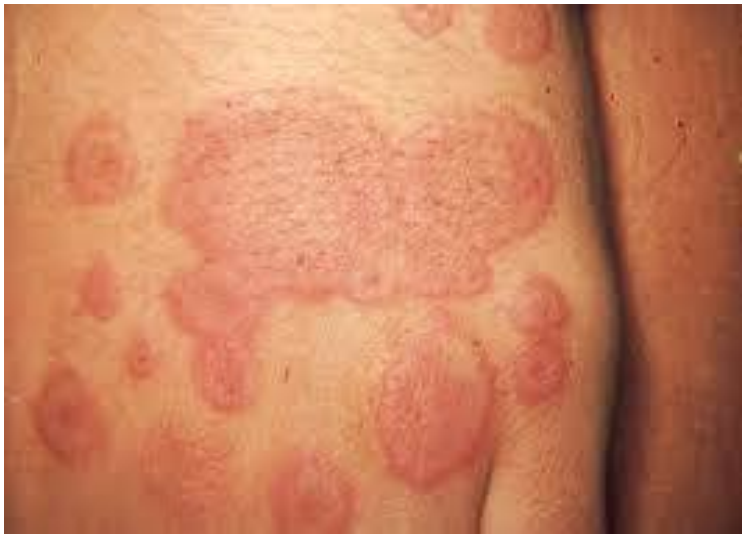
General Comment No 14

- Obligations flowing to State parties:
  - To respect (to refrain from interfering directly or indirectly with the enjoyment of the right to health)
  - To protect (to take measures to prevent third parties from interfering with health rights)
  - To fulfil (to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realisation of the right to health)

ARF Causes



- Results from abnormal autoimmune response caused by infection with Group A Streptococcus (GAS)
- The body generates antibodies to destroy GAS bacteria but because of the close similarity between parts of the bacterial cell's wall and heart tissue, the antibodies can also act against heart valves, leading to stenotic or regurgitant valves
- ARF and RHD more common in females
- ARF most common in adolescence and comparatively rare in those <5 and >35

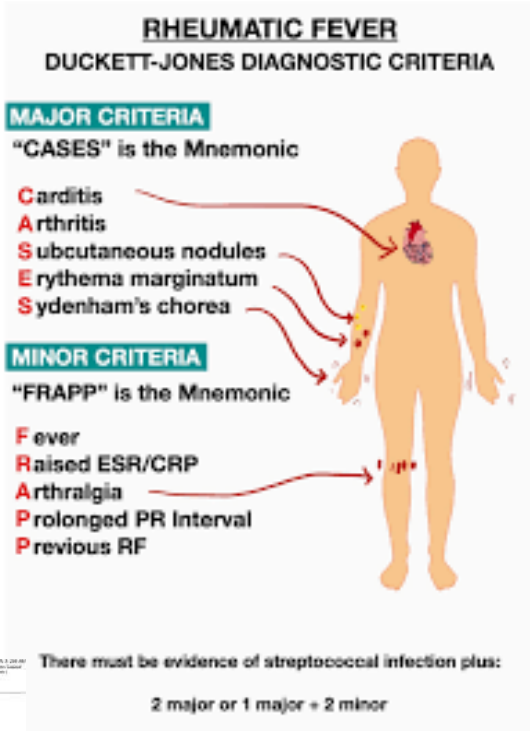


Aetiologies of ARF

- Untreated
  - Throat infections
  - dental caries
  - Streptococcal skin infections (impetigo or pyoderma)

ARF diagnosis

- Duckett-Jones criteria (1944):
  - Carditis
  - Arthritis (migratory arthritis)
  - Sydenham's chorea
  - Erythema marginatum
  - Subcutaneous nodules
- American Heart Association amendments (1992, 2015)

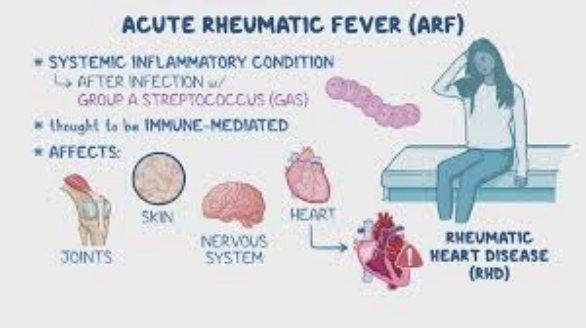


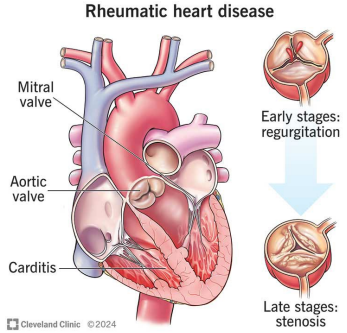

Editorial

Rheumatic fever—T. Duckett Jones and the rest of the story

ARF & RHD

- Without treatment c3% with streptococcal pharyngitis will develop ARF
- ARF leads to illness characterised by joint pain & swelling, cardiac valvular regurgitation, chorea, raised inflammatory markers, fever etc
- RHD: a complex multifactorial disease arising from the interaction between multiple genetic factors, GAS infection and the resulting uncontrolled inflammatory response
- RHD is the most common cause of heart-related death in children and adults <40

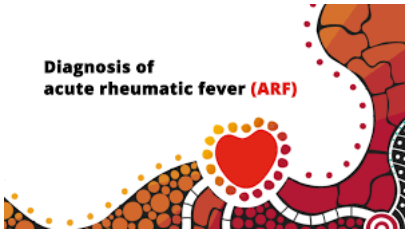




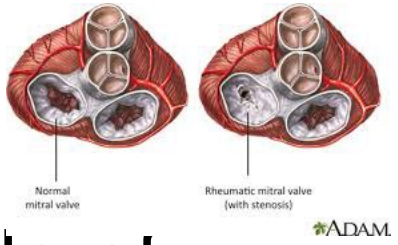
ARF/RHD public health responses

- Primordial, focusing on social determinants (hygiene, overcrowding, poor nutrition, wastewater safety)
- Primary, effective treatment of all GAS infections
- Secondary, regular injections of Benzathine Benzylpenicillin (BPG) after initial attack of ARF, and adoption of steps to enhance treatment compliance
- Tertiary, provision of care to alleviate symptoms, including surgery

RHD



- Damage done by ARF to cardiac valves is irreversible



- Can be from a single severe episode of ARF but more commonly from recurrent episodes
- Prompt care of GAS with oral penicillin reduces the rate of contracting ARF by c70% and by 80% if single BPG injection

BPG Injections

- BPG injections should be administered to those with ARF every 3-4 weeks for up to 10 years or up to 21 to prevent colonization of GAS and development of recurrent ARF, but if no carditis,5 years
- Global BPG adherence: 46%
- 2021 Australian Indigenous patients' adherence to 3-4 weekly BPG injections:
  - 18% received 100%
  - 13% received 80-99%
  - 27% received 50-79%
  - 41% received < 50% of prescribed doses

Areri, 2024: Barriers to BPG Adherence

- Fear of an allergic reaction to benzathine penicillin
- Patient-related factors such as limited healthcare access, living in rural areas, distance from healthcare facilities, poor communication between patients and healthcare providers, and fear of pain;
- A lack of family support,
- Conscious refusal,
- Lack of reminders
- Inadequate knowledge of healthcare providers to diagnose and manage RHD-related conditions;
- Shortage of BPG inadequate availability of staff;
- Negative perceptions of secondary prophylaxis;
- Inadequate counselling and distance

RHD Morbidity and Mortality

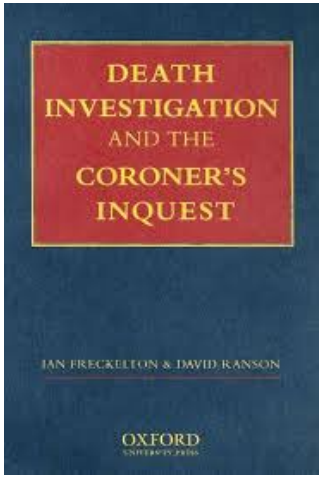
- NT RHD Register in Aus showed young people with rapid disease progression
- 50% with severe RHD required surgery within 2 years
- 10% deceased within 6 years; mortality at 10 years: 22%
- A 2021 retrospective study (Stacey et al) with 1,718 participants with initially uncomplicated RHD found that 23.3% of cases resulted in death or cardiovascular complications within 8 years

RHD as a public health issue

- A disease of overcrowding, poor hygiene, inadequate primary prevention and low adherence to secondary prophylaxis
- De Loizaga et al (2021) JAHA: a disease of deprivation
- In Australia 1 January 2022, 6,479 living with RHD
- 29% < 25
- 78% Indigenous

Coroners' Inquests

- Public, formal, court-auspiced investigation into unexpected, unnatural or suspicious deaths
- Opportunity to scrutinise deaths occurring in problematic circumstances, to clarify the public record and make recommendations for improvements to public health



ARF & RHD Inquests in Australia

- Forbes (NT): 2011; 37 yr old Aboriginal man
- James (Qld): 2015: 5 yr old child
- CNR (WA): 2017: 16 yr Aboriginal old child in care
- Yeeda (WA): 2022: young Aboriginal man in prison
- Tafau (NSW): 2022: 24 yr old Samoan man
- Doomadgee Cluster (Qld): 2023

Doomadgee Cluster Inquest (Qld): 2023

Doomadgee Cluster Inquest (Qld): 2023 , Coroner Wilson

- Deaths of 3 Indigenous women
- "Betty", who died from RHD at the Doomadgee Base Hospital in 2019, aged 18, having been diagnosed only two months earlier;
- Ms Sandy, who also died of RHD at the Doomadgee Base Hospital aged 37, having been diagnosed with ARF some time before she turned five; and
- Kaya, who died in 2020 at the Queensland Children's Hospital, Brisbane, aged 17 from an intra-cerebral haemorrhage, multi-organ failure, and lack of anticoagulation therapy after the repair of her aortic right ventricle as a consequence of chronic RHD, having developed RHD after ARF in 2009.

Doomadgee Cluster Inquest (Qld): 2023 , Coroner Wilson

- RHD is 100% preventable

  RHD is prevented by the most simple and basic measures of health and hygiene including washing of hands, washing of clothes, regular showering /bathing, and early treatment of sores and fever. In general terms, social determinants, a lack of basic health education, and awareness, overcrowding, and a lack of 'health hardware' impacts the outcomes for those with rheumatic heart fever and rheumatic heart disease
- 3,600 active clients on the Qld RHD Register, 68% ATSI
- People of Doomadgee do not have any ready access to adequate washing machines, beds and quality produce
- As between health service providers there was confusion as to which service was responsible for care and management, including administration of BPG injections and sharing of health records
- Health system was fragmented & responsibility for oversight needed to be integrated and communication improved

Doomadgee Cluster Inquest (Qld): 2023, Coroner Wilson

From a global perspective by almost all criteria indigenous Australians are one of the most vulnerable populations on earth. If however you are an indigenous Australian living in Doomadgee that vulnerability is heightened. The people of Doomadgee were placed in that location by a State government only relatively recently. There is no economy there is no industry. The old people speak historically of there being no illness. Betty's parents in their oral family statement said that as a result of illness, you can now hear the young people breathless walking home from school in Doomadgee.

The health systems and processes that might work elsewhere do not work in Doomadgee, they have "not been contextualised for indigenous communities nor with provision for indigenous cultural approaches to maintain health and wellness". The complexity is almost beyond the limitations of non-indigenous understanding

Doomadgee Cluster Inquest (Qld): 2023, Coroner Wilson

- Multiple recommendations for systemic reform of processes, integration, co-ordination and resourcing
- No findings of systemic or institutional racism
- Significant subsequent governmental responses: too early to evaluate sufficiency and follow through of reforms

The ARF & RHD Inquests

- Have highlighted significant deficiencies in diagnosis & treatment, relationships between health services, transfer options, referral protocols and co-ordination of care
- Shortfalls disproportionately affect Indigenous patients
- Have shone a confronting light on accommodation, nutrition, hygiene & access to safe living conditions that are dangerously conducive to Strep A infections
- Need for ongoing public health law scrutiny by further coroners' inquests to identify whether Australia is meeting its international obligations