

Health literacy and healthcare system navigation for people who have had, or are at risk of, a cardiac condition: Findings from an Australian study

Background of the Project

Healthcare navigation is the process by which people move into and through the multiple parts of a healthcare system to gain access to and use the services it provides. For those with low health literacy the challenge of navigation may prove as great a burden as the task of staying well, especially given the navigational demands made on those skills by complex healthcare systems and the requirements of chronic disease management.

Varyingly defined as the ability to access, understand and apply health information, the skills of health literacy are inextricably linked to the process of navigation. Data from the most recent Australian survey of health literacy, the 2006 Adult Literacy and Lifeskills Survey (ALLS), reveal 60% of people aged 15 to 74 years do not have adequate health literacy. The reality of those data is stark given the well documented implications of low health literacy and the fact Australia's healthcare system is characterised by its complexity and rates of chronic disease are burgeoning among its population. Whilst in the USA a similar reality promulgated healthcare navigation programs aimed at addressing patient barriers to care such as low health literacy, in Australia's states and territories the responsibility for healthcare navigation devolves to the individual.

The Project

Objective: To determine the viability of health literacy as a focus for intervention to better equip people with the skills and abilities needed for healthcare navigation in the context of managing a chronic cardiac disease.

Three questions supported that objective. Principally:

- Do participants' health literacy scores contribute to an understanding of their experience of navigating a healthcare system to manage their cardiac ill health?

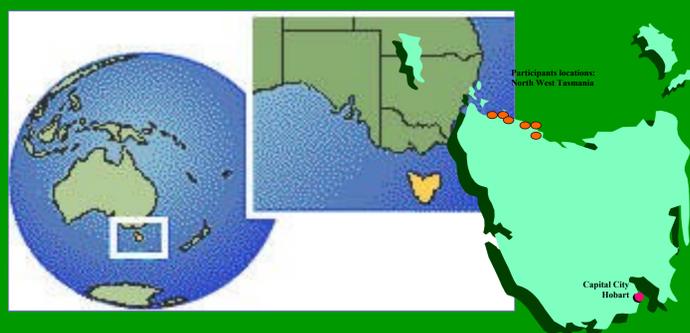
In order to answer that question the responses to two precursory questions were necessary:

- How do participants score on health literacy?
- What is the experience of navigating a healthcare system like for people who have had, or are at risk of, a cardiac event?

Design, setting and participants: Retrospective, mixed methods survey administered in 2010 to a volunteer sample population of 12 adult males and 6 adult females, all of whom lived in regional towns across the North West Coast of Tasmania, Australia (Figure 1). They participated in a community-based cardiac rehabilitation program as a result of being at risk of, or having had, a cardiac event.

Main outcome measures: Newest Vital Sign (NVS) as a measure of health literacy; self-reported navigation of the Tasmanian healthcare system.

Figure 1.
Participants' residential locations across North West Tasmania



Project Team

Rural Clinical School, University of Tasmania - Doctor Winifred van Der Ploeg, Professor Judi Walker¹, Doctor Ali Maginness
Menzies Research Institute, University of Tasmania - Professor Joan Abbott-Chapman

¹Professor Judith Walker is now at the School of Rural Health and Gippsland Medical School, Monash University, Australia.

Summary of the Findings

The majority of participants (n = 14) had NVS scores suggesting limited health literacy. Participants' age and gender were correlated with their scores and are presented in Table 1.

A similar majority (n = 16) reported largely positive navigational experiences that were expressed, or implied as proportional to their confidence in being able to navigate the healthcare system.

The amalgam of those findings answered the principal question of whether participants' health literacy scores on the NVS made a contribution towards understanding their experiences of healthcare navigation. To an extent they did because compared to participants with adequate health literacy, those with limited health literacy had:

- less cardiac knowledge and awareness of treatment protocols as well as
- less self efficacy when it came to filling out health-related forms, reading hospital materials and learning about their cardiac conditions, all of which impacted their navigational experiences.

Table 1
Participants NVS scores correlated with their age and gender

	NVS scores *		
	0 to 3 (%)	4 to 6 (%)	Total No. (%)
Age			
Under 65	5 (35.7%)	3 (75.0%)	8 (44.4%)
65+	9 (64.3%)	1 (25%)	10 (55.6%)
TOTAL	14 (100%)	4 (100%)	18 (100%)
Gender			
Male	8 (57.1%)	4 (100%)	12 (67.7%)
Female	6 (42.9%)	0 (0%)	6 (33.3%)
TOTAL	14 (100%)	4 (100%)	18 (100%)

* 0 to 3 suggests limited literacy, 4 to 6 suggests adequate literacy

To a greater extent however, the data highlighted that whilst low health literacy had the potential to make navigation more difficult it could be sufficiently compensated by other factors impacting at the individual, service and system levels (eg. motivation, support, guidance, accessibility) to make the overall experience a positive and manageable one.

A framework was developed to illustrate those factors (Figure 2).

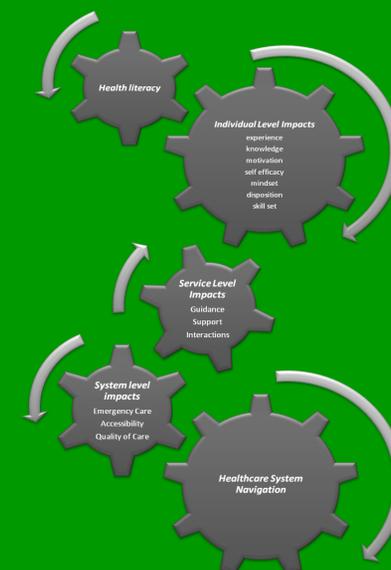
Why cogwheels?

- They depict the interrelated nature of the factors impacting participants' navigational experiences at the individual, service and system levels
- They depict the dynamic nature of healthcare system navigation
- To highlight the pervasive impact of health literacy on healthcare system navigation at the individual level

Implications of the Findings

Health literacy as a focus for intervention to better equip people with the skills and abilities needed for healthcare navigation would need to be part of a multifactorial strategy that took into consideration the other individual, service and system level factors shown to impact the navigation experience given their interrelated nature.

Figure 2
A framework for understanding the factors impacting participants' navigation of the Tasmanian healthcare system



Participant Quotes

The more knowledge you've got of what's going on the easier it is to understand...the medical system, the way it works.

I feel embarrassed that I don't understand.

I just do as I'm told.

I've found...going through emergency is the quickest way to get to where you want to go...going to your GP with a heart problem is...a waste of time because...they don't want to investigate it any further. It always seems to be the soft option, we'll sit back and wait.

I feel like I'm only asking...a petty little thing and why waste their time when they've got more important things to take care of...I'm only one of the numbers.

I leave...things to the extreme limit before I ask or seek information about something.

...he was so rude and he upset me so much...in the finish I said no, I'll stop here, I'll stay home.

The best thing I did was join the [CRP] because...we're exposed to health professionals...if we need help we know where to go...I know people I can contact.

Sometimes when [the healthcare system] goes wrong you are, like I am, very quick to criticise but in the long run it is the system...sometimes it works well, sometimes it doesn't...I accept the system for what it is. We'd love to make it better but then people tell you they haven't got the staff, they haven't got money, they haven't got this, that and everything else so you've got to go with the system as it exists.



Address for Correspondence

Dr Winifred van der Ploeg
Rural Clinical School
University of Tasmania
Private Bag 3513,
Burnie, Tasmania
Australia 7320
E-mail: wjv@utas.edu.au

