Health literacy and healthcare system navigation for people who have had, or are at risk of, a cardiac event

Winifred van der Ploeg
MHlthSc (OT) BAppSc (OT)

Submitted in fulfillment of the requirements for the Degree of Doctor of Philosophy

University of Tasmania
April 2012
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ABSTRACT

As the first study looking at health literacy and healthcare system navigation in Tasmania, the findings make a significant contribution to Australian-based health literacy research. Derived from a mixed methods survey of 18 mostly senior, regional participants with cardiac ill health, the data revealed a group for whom the abilities to access, understand and apply health information were largely inadequate. Yet remarkably, in light of that finding, most participants' experiences of healthcare system navigation were positive and most spoke with confidence about being able to perform the task. Participants' recollections were examined for factors that contributed to their experiences.

Analysis of the individual, service and system level themes that emerged from participants' recollections produced a complex picture of factors understood to impact their navigational experiences. In seeking to interpret and explain that complexity a framework was developed which highlights the role of health literacy at the individual level. The cogwheels depicted in the framework represent the interrelated nature of the factors impacting navigation at the various levels; the dynamic nature of healthcare navigation; and the influence health literacy may have on it.

That said, the contribution participants' health literacy made towards understanding the complexities of their navigational experiences were both conclusive and inconclusive. Conclusively, the data revealed a positive association between participants' health literacy and their depth of cardiac knowledge and subsequent ability to respond appropriately when symptomatic; their understanding of treatment protocols; and their self efficacy with filling out forms, reading hospital materials and learning about their cardiac conditions. However, data analysis revealed that in many ways the contribution participants' health literacy made towards understanding their navigational experiences was inconclusive. Self
management motivation; advice and support with navigational decision making; and service accessibility, for example, were also shown to assist participants who achieved across the range of possible health literacy proficiencies.

Collectively, those findings evidenced the vulnerability of participants with limited health literacy whilst demonstrating health literacy was one of a number of factors impacting the healthcare navigation experience. Thus, although limited health literacy risked making navigation more difficult it could be offset by other factors such as motivation, advice, support and service accessibility to make the overall experience a positive and manageable one. From the findings of this study it is recommended health literacy is addressed as part of a multifactorial intervention strategy to improve individuals’ successful navigation of healthcare systems, whilst also advocating further research in the area.
ACKNOWLEDGEMENTS

It must be said that behind every doctoral candidate is a network of supporters without whom the point of completion would never arrive. They are the people who always listen with genuine interest; who know what to say to ensure a sense of perspective; who provide feedback that is both constructive and encouraging; and who always seem to have time. They are the people who are truly worth their weight in gold.

For me, those people have been Professor Judi Walker, Professor Joan Abbott-Chapman and Doctor Ali Maginness. A better combination of academic stewardship would be difficult to find. Likewise, the friendship of all who occupied the inner sanctum of the Rural Clinical School in Burnie – you made the days so much more pleasurable. I owe immense gratitude to the library staff of the North West Regional Hospital and University of Tasmania who responded diligently and without fuss to my numerous requests for literature. My thanks go also to the Coordinator of the Cardiac Rehabilitation Program for her willingness to allow me to encroach her clinical responsibilities and to the eighteen participants for allowing me to share their time and insights.

I struggle to find the words to express how grateful I am for the unwavering support of my parents (Eddy and Penny) and my sister (Lydia) over the past three years and for the charm of my niece (Zoe) and nephew (Brendan) in being able to make me smile.

Finally, I leave to last the very special person to whom this thesis is dedicated – my daughter Megan. More than anyone else, Megan has appreciated the implications of this undertaking and shown a level of maturity beyond her eight years that made her support fundamental to its completion. To my darling Megan, I thank you from the bottom of my heart.....at last we’re there.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>ACS</td>
<td>American Cancer Society</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<td>ALLS</td>
<td>Adult Literacy and Lifeskills Survey</td>
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<tr>
<td>ARIA+</td>
<td>Accessibility/Remoteness Index of Australia</td>
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<tr>
<td>ASGC</td>
<td>Australian Standard Geographical Classification</td>
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<tr>
<td>ASGS</td>
<td>Australian Statistical Geography Standard</td>
</tr>
<tr>
<td>AUROC</td>
<td>Area Under the Receiver-Operating Characteristics</td>
</tr>
<tr>
<td>COB</td>
<td>Country of birth</td>
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<tr>
<td>DoHA</td>
<td>Department of Health and Ageing, Australia</td>
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<tr>
<td>DHHS</td>
<td>Department of Health and Human Services, Tasmania</td>
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<tr>
<td>eHEALS</td>
<td>eHealth Literacy Scale</td>
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<tr>
<td>ED</td>
<td>Emergency Department</td>
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<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>HA</td>
<td>Heart attack</td>
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<td>IALS</td>
<td>International Adult literacy Survey</td>
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<tr>
<td>MM</td>
<td>Mixed methods</td>
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<tr>
<td>NAAL</td>
<td>US National Assessment of Adult Literacy</td>
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<tr>
<td>NHPAC</td>
<td>National Health Priority Action Council</td>
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<tr>
<td>NVS</td>
<td>Newest Vital Sign</td>
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<tr>
<td>OECD</td>
<td>Organisation for Economic Co-operation and Development</td>
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<tr>
<td>OHS</td>
<td>Open heart surgery</td>
</tr>
<tr>
<td>PIAT</td>
<td>Peabody Individual Achievement Test</td>
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<tr>
<td>QUAL</td>
<td>Qualitative research</td>
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<tr>
<td>QUAN</td>
<td>Quantitative research</td>
</tr>
<tr>
<td>REALM</td>
<td>Rapid Estimate of Adult Literacy in Medicine</td>
</tr>
<tr>
<td>RDI</td>
<td>Recommended dietary intake</td>
</tr>
<tr>
<td>SAL</td>
<td>Survey of Aspects of Literacy</td>
</tr>
<tr>
<td>SBSQ</td>
<td>Set of brief screening questions</td>
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<tr>
<td>SORT</td>
<td>Slosson Oral Reading Test</td>
</tr>
<tr>
<td>TasCOSS</td>
<td>Tasmanian Council of Social Service</td>
</tr>
<tr>
<td>TOFHLA</td>
<td>Test of Functional Health Literacy In Adults</td>
</tr>
<tr>
<td>TSI</td>
<td>Torres Strait Islander</td>
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<tr>
<td>USA</td>
<td>United States of America</td>
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<tr>
<td>USDHHS</td>
<td>US Department of Health and Human Services</td>
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<tr>
<td>WRAT</td>
<td>Wide Range Achievement Test</td>
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