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Multiple conditions: exploring literature from the consumer perspective in Australia

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Abstract

Background Following a workshop with people with multiple conditions, the Chronic Illness Alliance undertook a literature review to explore current literature about multiple conditions.

Methods The literature search was performed using Medline, CINAHL, Google Scholar and Cochrane Library employing an extensive list of search terms and limited to English language journals between 1999 and 2009. Inclusion criteria for articles were those articles focussing on issues identified by consumers with more than one chronic illness and the health services working with them.

Results The results reported in this article are definitions of multiple conditions, safety and quality of services, risks and benefits of treatments for multiple and rare conditions and coordination of services.

Discussion The impact of multiple conditions or multimorbidities on health services has been researched internationally and identifies the barriers to good health care when multiple conditions are not recognized. While the issues for consumers with more than one condition are not well recognized, the barriers identified by the literature are of great importance to consumers.

Conclusions This review demonstrates that services and policies in Australia require specific reforms to better meet the needs of people with multiple conditions.

Introduction

In Australia, the focus of recent health policies has largely been on the more common chronic illnesses, such as heart conditions, asthma, arthritis, COPD and Type 2 diabetes.[1,2] The reasons for this concentration on 'lifestyle' conditions are clear: they are prevalent in the community and they are largely preventable[1–4] although the new science of epigenetics may change prevention strategies.[5–7] However, chronicity is not confined to preventable conditions. There is a range of serious long-term illnesses which receive far less attention in health policy and funding, for example, Thalassaemia, Type 1 diabetes, leukodystrophy, epilepsy, multiple sclerosis and cystic fibrosis.

Health policy documents imply that 'lifestyle' conditions are the purview of primary care, while the more rare conditions are cared for by

specialist medical and tertiary services.[8] However, in practice, care is far more complicated. Primary care services see people whose health changes with time and situation. A person may be diagnosed with new conditions; require referrals and differing treatments and more social and health services.

There is increasing recognition that primary care requires support to work with multiple conditions[9–12] but this discussion rarely incorporates the experiences of people living with multiple conditions and the health services they access.

People's experiences of having multiple conditions, their experiences of the services they accessed and the improvements they thought could be made were the subject of a workshop in 2007.[13] Participants represented a range of 'lifestyle', rarer genetic and iatrogenic conditions and people with several unrelated conditions. They considered the health system often failed to appreciate the complexity of their health. The workshop identified directions important to people with multiple conditions for the Chronic Illness Alliance to explore. These included definitions of terms such as multiple conditions; the target populations with multiple conditions; safety and quality of services; the risks and benefits of treatments for multiple and/or rare conditions. This consumer-focused direction formed the search and analysis criteria of the literature review. Overall, the aims of the literature review were exploratory. Firstly, to identify issues related to above concerns identified by people with multiple conditions as impacting on their health and quality of life. A secondary aim was to identify any work undertaken to reduce the risks that concern consumers with multiple conditions.

Methods

The literature search and review was not a systematic review. Both financial constraints and the consumer-derived aims indicated a qualitative approach was more appropriate because needs of the consumers were more likely to be answered by what Harden *et al.* 2004:794[14] describe as 'intervention studies' that 'identify effective, ineffective and harmful interventions' and 'non-intervention' studies that discuss systemic issues associated with the quality of services consumers receive.

Systematizing qualitative work is a relatively new area where methods are still being developed and discussed.[15] Harden *et al.*[14] and Thomas and Harden[16] describe their method as beginning with the research question; conducting a systematic search for intervention and non-intervention studies and then holding a stakeholder consultation which refined questions; followed by in-depth review of those studies that were included. In-depth review was conducted according to the application of inclusion criteria. The final stage of their process was a synthesis of findings from the studies to answer the questions they had begun with. As a qualitative method, this process does not rely on an exhaustive search but rather on finding key or common concepts across studies and developing an argument from them.[17] Detailing the process allows others to replicate the work.

This project on multiple conditions began with the consumer consultation which defined their problems and established that consumers wanted to know what, if any work was being undertaken that would address these problems. Thus, the consultation delineated the above-mentioned aims, the inclusion criteria for literature and that a qualitative approach was most appropriate.

Search methods associated with systematic literature searching and article identification were employed to enhance the quality of the work. Medline, CINAHL, Google Scholar and Cochrane Library databases were searched between January 2000 and June 2009. Only English language journals were searched.

'Multiple conditions' are not used in medical and health service literature; it remains here as it is the term agreed by the Multiple Conditions Workshop as the most encompassing. An initial search on consumer issues and consumer perspective in combination with the above

terms produced no results. It was necessary to adopt MeSH terms in order to search the literature.

The following terms were used to search: multimorbidity; multiple chronic conditions; multiple comorbidities; multiple morbidities; multiple medical conditions; complex chronic disease; complex care patient (Table 1).

Abstracts were reviewed independently by two research assistants. Inclusion related to how well abstracts met the search term criteria relating to multiples conditions, comorbidities, consumer experiences and perspectives, safety and quality, definitions of the terms, primary care and specialist services, coordinated care, risks and benefits of treatments, care of rare conditions and the relation between multiple conditions and depression. Full texts were assessed for inclusion by the author in association with research assistants. Articles were included that best met the identified issues raised by consumers. There were no articles that focused on the consumer experience of living with multiple conditions. From a total of some 40,000 articles, a manual search produced 88 articles.

While Harden *et al.*[14] established quality criteria for inclusion of articles such as whether an article had a theoretical framework or clearly described the methods; this project had a different intention to that of assessing the quality of evidence. Identifying the recent trends in thought about the care of multiple conditions can be seen as a preliminary step to that of any discussion of quality.

With regard to the analysis of data, the 88 articles selected were not exhaustive; this was a purposive sample because in qualitative analysis the purpose is interpretive rather than predictive.[18] Working from principles of grounded theory[19] where the contents of articles speak for themselves, coding, based on the above consumer-derived terms was undertaken with each article. These were then combined into themes which emerged as problems of terminology, data and prevalence of multiple conditions, problems of multiple conditions for health services and the care of people with multiple conditions including quality and safety issues and coordinating care. These themes are recorded below as the results.

Results

Problems of terminology, data and prevalence of multiple conditions

There were different terms applied to 'having more than one condition'. At times, these were used without definition. Terms such as multiple morbidities, multimorbidities and comorbidities were employed. Table 2 provides some

Table 1 Refined search terms

1.	'rare conditions' OR 'rare illnesses' OR 'rare diseases' OR 'chronic illnesses' OR 'chronic conditions' or 'chronic diseases' AND depression OR anxiety;
2.	'comorbidity' AND 'rare conditions' OR 'rare illnesses' OR 'rare diseases' OR 'chronic illnesses' OR 'chronic conditions' OR 'chronic diseases' AND 'depression' OR 'anxiety';
3.	Australia AND comorbidity AND 'rare conditions' OR 'rare illnesses' OR 'rare diseases' OR 'chronic illnesses' OR 'chronic conditions' OR 'chronic diseases' AND depression OR anxiety;
4.	Self-care AND comorbidity AND 'rare conditions' OR 'rare illnesses' OR 'rare diseases' OR 'chronic illnesses' OR 'chronic conditions' OR 'chronic diseases' AND depression OR anxiety;
5.	Self-care AND Australia AND comorbidity AND 'rare conditions' OR 'rare illnesses' OR 'rare diseases' OR 'chronic illnesses' OR 'chronic conditions' OR 'chronic diseases' AND depression OR anxiety;
6.	Multimorbidity AND 'rare conditions' OR 'rare illnesses' OR 'rare diseases' OR 'chronic illnesses' OR 'chronic conditions' OR 'chronic diseases' AND depression OR anxiety;
7.	'self-efficacy' AND 'rare conditions' OR 'rare illnesses' OR 'rare diseases' OR 'chronic illnesses' OR 'chronic conditions' OR 'chronic diseases' AND depression OR anxiety;
8.	'Self-efficacy' AND comorbidity AND 'rare conditions' OR 'rare illnesses' OR 'rare diseases' OR 'chronic illnesses' OR 'chronic conditions' OR 'chronic diseases' AND depression OR anxiety.

Table 2 Examples of the terms found in literature: their definitions and meanings

Terms used	Defined and used according to definition	Comorbid/multimorbid	Notes
Chronic medical conditions/comorbidities	Bayliss *et al.*[20]		
Coexisting chronic conditions		Egede[21]	Not clear whether comorbid or multimorbid
Comorbidities		Van Weel and Schellevis[22]	Coexisting also used; uncertain if this is separate meaning to comorbid
		Verbrugge *et al.*[23]	In contrast with above this article defines comorbid as 'several conditions simultaneously'
Comorbid chronic illnesses		Bayliss *et al.*[24]	Multiple chronic medical conditions used in title; uncertain if referring specifically to comorbid or more broadly to multimorbid illnesses
Complex chronic diseases	Sevick *et al.*[25]		Defined as multiple morbidities; signifies new direction of research identifying complex needs
Concurrent chronic illnesses		Williams and Botti[26]	Used as comorbid
Concurrent chronic conditions	Fortin *et al.*[10]		Includes concepts of comorbidity and multimorbidity
Concurrent medical conditions	Fortin *et al.*[27]		Includes the concepts of comorbidity and multimorbidity
Burden of chronic disease	Bodenheimer *et al.*[28]		Defined as having more than one chronic condition
Multiple chronic diseases		Walker[29]	Defined as comorbid
Multimorbidity	Van Den Akker[9]		Defined as co-occurrence of two or more diseases in person without a defined index disease
	Smith and O'Dowd[30]		As above but examples in article might be seen as comorbidities
	Ritchie[31]		Simultaneous existence of more than 1 pathophysiologic condition
Multiple morbidity	Schoenberg *et al.*[32]		
Multiple conditions	Fortin *et al.*[11]		Multimorbidity used in title; multiple chronic medical conditions used in article
Multiple coexisting medical conditions		Laux *et al.*[33]	Appears not to distinguish between comorbid or multimorbid because research based on episodes of care
Multiple chronic conditions		Higashi *et al.*[34]	Article discusses quality of care based on number of medical conditions without distinguishing whether comorbid or not.
Multiple chronic health conditions		Loeb *et al.*[35]	Multiple chronic conditions used in title, then, article combines this with multiple chronic health conditions
Multiple chronic illnesses	Parchman.[36]		

Table 2. Continued

Terms used	Defined and used according to definition	Comorbid/multimorbid	Notes
Multiple chronic medical disorders		Piette *et al.*[37]	Multiple chronic illnesses used in title; multiple chronic medical disorders used in article; article discusses diabetes and comorbid depression; suggests the conceptual framework suitable to multiple chronic medical disorders
Unrelated disorders		Redelmeier *et al.*[38]	Title uses unrelated disorders. Article does not distinguish between comorbid or multimorbid; deals with treatments related to index disease

examples of these different terms and whether they were defined in the context of the article. The table illustrates the broad uses of these terms in the articles and is not exhaustive.

At times, the various phrases in which 'multiple' were combined with other terms appeared to be interchangeable with comorbidity. Fortin *et al.*[39] define multimorbidity as multiple coexistent diseases; Mercer *et al.*[40] define multimorbidity as the coexistence of two or more long-term conditions in an individual; Ritchie[31] defines multimorbidity as the 'simultaneous existence of more than one pathophysiologic condition or clinical entity'; Min *et al.*[41] define multimorbidity as multiple coexisting chronic conditions. This may be compared with the following definitions of comorbidity. Verbrugge *et al.*[23] define comorbidity as 'several chronic illnesses simultaneously'; Droomers and Westert[42] define comorbidity as the 'concurrence of multiple health conditions in one person'. However, van den Akker *et al.*[9] distinguished between comorbidity ('the existence or occurrence of any distinct additional entity during the clinical course of a patient who has the index disease under study') and multimorbidity ('the co-occurrence of multiple chronic or acute diseases and medical conditions within one person'). Jowsey *et al.* used a similar definition of comorbidity.[2]

The problem of inadequate data collection tools became evident where those authors attempted to estimate the prevalence of multiple conditions in large populations. Schoenberg *et al.* claimed that over 60 million Americans have 2.2 chronic diseases.[32] This increased from 58% to 70% between 1998 and 2002. Fortin *et al.*[11] identified the problem of valid data on the extent of multimorbidity in family practices in Canada. In attempting to rectify this, the authors counted the number of conditions, then used a severity rating scale and concluded that multimorbidities were more common in primary care than were single conditions. Fortin *et al.*[39] forecasts that 81 million Canadians will have multimorbidities by 2020 based on a sample from Quebec, Canada. At the same time, Broemeling[43] claimed there were 9 million Canadians managing chronic conditions in the first decade of this century. Using survey data from the Canadian Community Health Survey, the authors found those with more than one chronic condition used health services more than other Canadians. Starfield *et al.*[44] found they had to make arbitrary decisions about which was the index disease in exploring comorbidities.

Jewell *et al.*[45] used the Charlson Comorbidity Index (CCI) to determine the association between medical comorbidity and the number of tests for related conditions. They concluded that more research was required to determine whether all patients with varying comorbid illness burdens should receive equally aggressive care as it was difficult to determine if all were equally benefited. Smith, Ferede and O'Dowd[46] considered that current forms of disease classification and coding created barriers to the research and care of people with multimorbidities. Disease coding was inconsistent while GP

software was not helpful. Laux *et al.*[33] undertook analyses of the health utilization patterns of nearly 40,000 people with co or multimorbidities. They concluded that data structure was an essential means to build a basis to understand the needs and health utilization of people with co or multimorbidities.

The problems of multiple conditions for health services

Much of the literature was focused on primary care or discussed the issues of caring for people in community settings. Of the 88 articles, 38 discussed comorbidities in primary or community care in the United Kingdom, United States, Canada and Australia. Fortin *et al.*,[10] Van Weel and Schellevis[22] and possibly Smith and O'Dowd[30] were concerned with the prevalence of comorbid conditions in primary care and the implications this prevalence poses for good care. Other articles[47–49] explored the changes that were required in primary care settings to deal more effectively with comorbid conditions.

There was recognition that elderly people with comorbid conditions were not well served by the health system generally.[50] Verbrugge *et al.*[23] saw comorbid conditions as a trait of the elderly, leading to disability. Wolff *et al.*[51] used a Medicare (US) sample of over 1 million people aged 65 and over to explore the correlation between numbers of comorbidities and hospitalizations of older people. A similar study was carried out in Germany where age and multimorbidities were found to have strong impacts on use of services 25. Unplanned hospital admissions were discussed in relation to comorbidities and the elderly.[26,30,52,53] Upshur *et al.*[54] also argued that increased age added to the need to reconfigure primary care services. In contrast, Min *et al.*[41] explored whether older people with multiple chronic conditions were at high risk of receiving poorer quality care generally and arrived at the conclusion that older people with multiple conditions were more likely to receive better quality care.

Care of people with multiple conditions

Articles generally concluded that the current structure of the health system was inadequate for the care required by people with multiple conditions.[55–58]

Van Weel and Schellevis[22] pointed to the fact that guidelines in primary care were usually for single conditions. In people with more than one condition, recommended treatments may negatively interact with one another. They suggested replacing single disease guidelines with a patient-centred approach where various disease perspectives were integrated. Safford *et al.*[59] pointed out the need to make trade-off decisions to achieve patient-centred care. Problematically, evidence-based guidelines rarely provided guidance for trade-off decisions. Upshur *et al.*[54] also argued that increased age adds to the need to reconfigure primary care services. Ostbye *et al.*[55] estimated the time needed to provide optimal care in primary care for people with chronic conditions if guidelines were followed astutely. They concluded there was not enough time to implement good care for comorbidities according to guidelines.

There was also some recognition of problems arising from the silos between primary and specialist care in the United States, United Kingdom and Canadian health systems.[57,58] Starfield *et al.*[60] explored patterns of visits to both primary care physicians and specialists by adults and young people. They found that resource use depended on the degree of comorbidity rather than the diagnosis. While the number of visits to primary care physicians was higher than visits to specialists, those with rarer conditions were more likely to have more visits to specialists. The authors concluded that single disease management was not a helpful way to care for people with comorbid conditions. New patterns of care were required that work with patient well-being and integrated specialist and primary care.

Elderly people with comorbidities had a different pattern of primary care/specialist care usage. Starfield[48] found that worse levels of health were associated with a greater ratio of

specialist care in the United States. She concluded that a higher morbidity burden led to higher use of specialists even where the morbidity was associated with common diagnoses not generally requiring specialist care.

Stille *et al.*[59] suggested that research was required to develop coordinated care across all areas of care including specialists in the United States. They regarded coordinating care as the key role of general practice. In contrast, a UK-based article[61] argued for linkages rather than coordination. Effective care teams produced greater linkages between the various forms of care in the UK NHS, where only the most severe and complex cases were seen by specialists, while others were managed in primary care. There was little incentive to develop these linkages since joint work was not rewarded. The authors concluded that this needs to change so that specialist knowledge is more accessible.

No articles specifically discussed the role of health services in caring for people where rare conditions were associated with multiple conditions. Eurordis surveys indicated that people with rare conditions were subject to delayed diagnosis and multiple conditions which put them at risk in their health care.[62]

Discussion

This literature review identified articles that discussed multiple conditions from the point of view of the delivery of health services, namely the limitations in health services to deal effectively with multiple conditions. There were few articles specifically discussing the effects such limitations have on the lives of people living with multiple conditions, although many articles recognized that improving health service delivery would improve people's care. No articles were written from the consumer perspective or by consumers.

The problem of no consistent definition of multiple conditions was compounded by confusions between comorbidity and multimorbidity. In the literature reviewed, these terms might be used interchangeably. Feinstein identified in 1970 that a comorbidity existed where some conditions are in secondary relation to an index condition.[63] The situation is now more complicated. Some people simply have more than one condition, neither related to the other; others have conditions related to their treatments as in the cases of thalassaemia, bone marrow transplants and cystic fibrosis. Others may have another condition caused by an adverse event. Distinguishing between multiple conditions and comorbidities is now required to meet the changing chronic illness fields.

Such a distinction would assist with overcoming some of the difficulty of data collection. For those such as Smith *et al.*,[30] Fortin *et al.*[10,11,39] who have attempted to estimate the prevalence of multimorbidities in health systems whether a condition exists in its own right or whether it is associated with an index condition is problematical. It is these situations where both health professionals and consumers alike are in need of assistance from a better tool.

Guidelines pose obstacles for both health professionals and consumers. It is evident from articles talking of trade-offs between guidelines, lack of time to use them effectively and decisions about referrals to specialists that in the face of either comorbidity or multiple conditions, primary care health professionals practise a level of improvisation and rely heavily on their clinical judgment. Single condition guidelines do not assist health practitioners regarding polypharmacy and drug interactions. In some cases, single condition guidelines may lead to confusion in diagnosing whether conditions are comorbid or entirely new unrelated conditions. There were no suggestions in the literature on how to improve guidelines beyond recognizing the need for holistic care. Yet, how this is to be carried out remains at best vague. For consumers, these areas of safety and quality are of paramount concern because adverse events or incorrect diagnosis may have serious consequences.

While efforts to coordinate primary and specialist care have been made in Australia, little has been achieved. For people with both rare and multiple conditions, lack of coordination may mean lack of referral to a range of services

or duplication of services such as imaging and pathology. It may contribute to conflicting advice from primary care providers and specialists as well as problems related to prescribing.

Much of the literature concentrates on multiple chronic conditions and the elderly reflecting health policy concerns. Given the association between multiple conditions and unplanned emergency department, admissions in the elderly[51–53] such a concern requires addressing. For those who are not elderly but have multiple conditions, unplanned hospital admissions are also an issue[46]. In some instances, unplanned hospital admissions take place because many services are largely designed and funded to meet the needs of the elderly.

Participants in the Chronic Illness Alliance workshop on multiple conditions identified that problems arose from the current structure of the Australian health system which was not adequate to meet the needs of people with multiple conditions. They identified that solutions to the problems they faced required health services reform. In the main, literature in this review reached similar conclusions. Most articles identified the gaps and barriers for people with multiple conditions but few articles explored solutions beyond recommendations. Williams and Botti, for example, conclude that 'further research is necessary to explore how episodic care is integrated into the on-going management of patients with comorbidities and how nurse clinicians can better use an episode of acute illness as an opportunity to review their overall management'.[26] Bayliss et al consider the ideal care for older people with multiple conditions is patient-centred, individualized care with a single coordinator.[50] Removing single condition guidelines and replacing them with something that produced holistic patient-centred care was also a strong recommendation in literature regardless of the health system although specific recommendations were lacking.

Conclusion

The literature shows problems related to confused definitions, accurate data and identification of people with multiple conditions or comorbidities. These problems as well as treatment interactions and poorly coordinated services are recognized in the health systems of the United States, United Kingdom, Netherlands, Germany and Canada. They are becoming recognized as having some urgency in the Australian system through the health reform process.[2,12]

Whereas the literature demonstrates a similarity in problems, internationally each health system has unique features and challenges. These unique features impact on consumers with multiple conditions. In Australia, far more exploration of the problems related to services for people with multiple conditions is needed. It needs to be undertaken with consumers who know complexity of the problems from first-hand experience. Such consumers are not a homogeneous group. They are people with rare conditions who have developed other conditions as a side-effect of treatment or from an adverse event; people who have comorbidities; people who have several unrelated conditions; they are young people or the elderly; their conditions may be related to lifestyle issues or to genetics or the environment.[48] This level of complexity is not recognized in health policies, and consequently, consumers and practitioners working with complexity require new models of care applied consistently and nationally.

As a start work of an exploratory nature would form the basis to accurately define multiple conditions and comorbidities as well as establishing a means to record and collect data, protocols on the care of people with multiple conditions would then replace single condition guidelines as well as assist to address safety issues of treatment interactions and poor coordination of services.

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Conflicts of interest

None.

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