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Cover Page Footnote

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Conceptualising multiple conditions in Australia: First steps to systemic change to meet the needs of people with serious long-term illnesses

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Abstract

Since the 1970s greater numbers of people are now living with several serious long term illnesses. These include rarer genetic conditions and 'lifestyle conditions' as well as those of an idiopathic nature. This article examines the growing need for new terms and concepts that reflect the changes in the lives of people living with long-term serious illnesses. Members of the Chronic Illness Alliance attended a workshop where they presented their experiences and views of living with multi-morbidities. Consumers were concerned about treatment side-effects, polypharmacy, adverse events and the need for coordinated care. Following this workshop, the Chronic Illness Alliance undertook a literature review using the principles of meta-synthesis to explore the consumer perspective in literature on multi-morbidities. This method aims to systematise qualitative concepts and it provided the means to identify whether the concerns raised by consumers were recognised in the literature. The risks identified by consumers were used both as search terms and analytical terms. While the consumer perspective appeared absent in the literature, many authors showed similar concern about the tardiness of health systems to acknowledge the impact of multi-morbidities for consumers and the associated risks. More importantly the literature review demonstrated that problems associated with concepts, definitions and data collection impact on health care and service delivery. This in turn dictates how consumers receive their health care services and ultimately influences the safety and quality of their health care. The article discusses the concepts of co-morbidity and multi-morbidity in relation to data collection, definitions and treatment guidelines and their implications for consumers with regard to treatments, side-effects, polypharmacy, adverse events and coordinating care. There is a pressing need to develop and employ concepts that better reflect consumers' needs and experiences in order to improve safety and quality of health care. The article argues that the adoption of better concepts is a first step to achieving systemic change on behalf of people with multiple conditions.

Keywords

Multiple conditions, multi-morbidities, consumer perspective, concepts, definitions

Introduction

This article examines the growing need for new terms and concepts that reflect the changes in the lives of people who are now living with long-term serious illnesses for far longer periods. The article articulates the needs of people living with long-term serious illnesses from health services and health policies to ensure that care is designed to promote as high a quality of life as possible. Overall the aims of this study are to articulate the needs of people with multiple conditions, the problems they face in the current health services context in Australia and to explore how people with multiple conditions might be better assisted.

Background

Griff is now in his early 60s. He retired some 8 years ago following a career in administration. He and his wife lead a life of social activity, family responsibilities and community involvement. While this might lead us to applaud Griff's decision to plan for an early retirement there is much more

in Griff's life for us to contemplate. Griff has hemophilia, which means a lifetime of replacement therapy and care at a specialist treatment centre. In Griff's case it has also meant musculoskeletal conditions associated with the joint damage caused by bleeds, and consequent surgery to many of his joints. He also developed Hep C from contaminated blood products supplied to him several decades ago. The fatigue of, and treatment for Hep C led to years of depression. Griff also has asthma, epilepsy and osteoporosis. Griff's working life and retirement has been punctuated by the time he spends at treatment centres and the money it costs in co-payments, transport and health insurance. Both he and his wife are fully aware of the value of having health professionals with understanding of the full range of his conditions and their treatments involved in his care and that this may sometimes be difficult to find. In many ways Griff's life encapsulates the problems associated with living with multiple conditions. It also suggests the path of health reform to deal adequately with these issues in the 21st century. Firstly such a path requires the means to capture the changing patterns of disease.

It is only relatively recently that health service research has recognised that data collection provides a means to improve service delivery through recognition of changing patterns of disease. Alvin Feinstein was a pioneer of this approach¹.

In 1970 Feinstein developed the concept of co-morbidity. Feinstein maintained that co-morbidity referred to 'any distinct additional clinical entity that has existed or that may occur during the clinical course of a patient who has the index disease under study'.

Feinstein's aim in elucidating these complexities was to provide a guide to both epidemiologists and clinicians. He argued that the lack of acknowledgment of co-morbidities had consequences for the collection of accurate statistics of diseases such as mortality rates and fatality rates for individual diseases.

Where clinicians were concerned Feinstein argued that ignoring co-morbidities impacted on the accurate evaluation of treatment. The customary evaluation of treatment by studying comparable groups of patients, usually in a single disease clinical trial, that excluded people with co-morbidities meant the results did not fit the 'real world'. Additionally, not recognizing the presence of co-morbidities affected the accurate diagnosis and treatment of an index disease, since co-morbidity could mask the index disease, thus delaying its diagnosis and appropriate treatment and ultimately impacting on the outcome of the index disease.

Feinstein's conceptual work has been integrated into the prevention, diagnosis, and treatment of many chronic illnesses such as type 2 diabetes, chronic obstructive pulmonary disease and chronic heart conditions, particularly in ageing populations. Since the 1970s however a major change has taken place whereby more people are living longer with chronic illnesses². This includes living longer with rare genetic illnesses, lifestyle-related conditions and idiopathic conditions^{3,4}. In the 25 years from 1973 to 1998, the survival of children with Cystic Fibrosis (CF) increased by seven hundred per cent while the survival of children with congenital heart disease had increased by three hundred per cent⁵. Whereas young people with genetic conditions such as CF had a life expectancy of about 18 years in the 1970s, young people now are graduating from tertiary institutions, marrying and having children. Cystic-fibrosis related diabetes has been a known co-morbid condition for some 50 years, but it is now a far greater problem for those who must live with it for some decades arising as it does as a result of the high fat diets, which assist people surviving CF⁶. In 2006 it was found that some sixty per cent of the US population aged over 18 had at least one chronic condition but this increases with age so that in the 65 and over age group

three out of four people have multiple chronic conditions⁷. The authors noted in 2005:

The proportion of adults with at least one chronic condition increased dramatically with age, ranging from 36.4 per cent of young adults age 18–34 to 91.5 per cent of the elderly age 65 and over. The proportion of persons with two or more chronic conditions also rose dramatically with age, ranging from only 14.4 per cent among persons age 18–34 to 76.6 per cent of the elderly age 65 and over.⁷

These statistics demonstrate that where lives might have been shortened by serious conditions in the past, people are now living much longer with those conditions and the longer they live the greater the likelihood of contracting other conditions. Much has been written on the costs to health systems of these changes and the need for health services to work with the changing profiles of ageing and chronic illnesses. However little has been written of the experience of living with more than one condition, the effects of treatments and how this compounds on people's quality of life.

As stated at the beginning this article examines the growing need for new terms and concepts that reflect the changes in the lives of people who are now living with long-term serious illnesses for far longer periods, because they are most likely the ones to develop multiple conditions. By articulating their needs and the problems they face in the current health services context in Australia new concepts and terminology can contribute to the development of health services and policies that work for people with multiple conditions.

Methods

Ethical approval

Ethical approval was sought subsequent to the workshop being undertaken and was provided by the Human Research Ethics Committee 2013/223 of Deakin University Australia, which determined that the project complied with the Australian National Statement on Ethical Conduct in Human Research (2007). Written informed consent is obtained for every workshop participant all of whom were over the age of 18, and able to comprehend the Plain Language Statement and Consent Forms.

Defining the problems faced by consumers

In 2008 members of the Chronic Illness Alliance, an Australian peak body which aims to build a better focus for all people with chronic illnesses in Australian health policy and health services held a workshop with its members to discuss the impact of living with 'more than one condition'. The workshop participants decided to refer

to this issue as 'multiple conditions' and the Alliance has retained this term instead of the terms multi-morbidities or multiple morbidities current in medical literature⁸. Participants had illnesses such as MS, Cystic Fibrosis, Thalassaemia, types 1 and 2 diabetes, depression, osteoarthritis and epilepsy. In all cases participants had other conditions as well as these index conditions. They collectively identified that people with multiple conditions were at risk of adverse events and unwanted complications. Their risks were related to:

- The number of medications they require, some of which may lead to drug interactions. An example of this is the interaction between some antiretrovirals and anti-epileptic drugs⁹. Additionally, medicines for one condition may lead to acquiring another condition such as treatment levels for hypothyroidism predisposing older people to osteoporosis¹⁰. Similarly, blood transfusions in Thalassaemia major can lead to liver failure¹¹.
- The unknown implications of treatments. In some cases treatment for a cancer may cause another cancer to develop many years later.
- Confusion over the diagnosis (such as health professionals in Emergency Departments confusing treatment of type 1 diabetes with treatment of Type 2 diabetes.)¹²
- The competing needs of caring for a number of different diagnoses in the one person where there is a need to prioritise which diagnosis is the most important one to concentrate on.
- The difficulty of accessing medical services where the person's entire medical situation is fully understood.
- People with multiple conditions are likely to be stressed, both financially and emotionally. Their ability to work may suffer; the costs of their care are likely to be far greater than others. The time required to self-care will contribute to this stress. They may be more socially isolated which contributes to stress and depression.

Workshop participants argued that these problems arose because health systems had not caught up with their changing needs. They considered new terms were needed to cover the complexity of living with more than one condition and a new definition was required. They requested the Chronic Illness Alliance conduct a literature search to explore if consumer experiences of living with multiple conditions were represented in health service literature.

Data Collection

Using the risks identified by workshop participants as the search term parameters, the aim of the literature review was to identify issues related to consumer concerns; definitions and concepts of multiple conditions; any work

undertaken to reduce the risks that concern consumers with multiple conditions. 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 for the period 2000 to 2009. Only English language journals were searched.

'Multiple conditions' is not used in medical and health service literature. It remains here, as it is the term agreed by the Multiple Conditions Workshop participants as the most reflective of their experiences. An initial search on consumer issues and perspectives in multiple conditions produced no results. It was necessary to adopt MeSH terms in order to search the literature. The following terms were used: multi-morbidity; multiple chronic conditions; multiple co-morbidities; multiple morbidities; multiple medical conditions; complex chronic disease; complex care patient.

Two research assistants reviewed abstracts independently. Inclusion related to how well abstracts met the search term criteria relating to multiple conditions, co-morbidities, consumer experiences and perspectives, safety and quality, definitions of 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 by the author in association with the research assistants. Inclusion criteria related to those articles that addressed issues of coordinated or uncoordinated care, polypharmacy, adverse events, discussions of multiple chronic illnesses and how these were being addressed in health services and policies, the consumer perspective of living with multiple conditions. There were no articles that focused on the consumer experience of living with multiple conditions. From a total of 40,000 articles 88 articles met the consumer-driven criteria. This was a purposive sample of articles as the approach was a qualitative one based on the more recent methods of meta-synthesis, discussed below.

Data analysis

The consumer-derived aims indicated a qualitative approach was appropriate since needs of the consumers were more likely to be answered by what Harden et al 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 receive¹³.

Systematising qualitative work is a relatively new area where methods are still being developed and discussed¹⁴. Harden et al and Thomas and Harden 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^{13,15}. 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 as in systematic reviewing. Instead it is a purposive search for key or common concepts across studies from which to develop an argument¹⁵.

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 provided consumer-driven terms from which to analyse the data.

While Harden et al 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.¹³ 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 since in qualitative analysis the purpose is interpretive rather than predictive.¹⁶ Working from principles of grounded theory where the contents of articles speak for themselves, coding, based on the above consumer-derived terms was undertaken with each article.¹⁷ 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

The results provided here are not quantifiable but the results of qualitative analysis. No articles were written from the perspective the consumer living with multiple conditions. However many of the problems experienced by workshop participants are discussed in the literature from the perspective of the quality of health service delivery. These discussions fall under the broad categories of accurate data and collection; accurate definitions; issues of disease-specific guidelines.

The problems of accurate data and data collection

Several articles focus on the prevalence of multiple conditions in primary care and the implications this prevalence poses for good care.^{18,19,20,21} In Canada it was

estimated that multiple conditions are most common in older people with some 98% of older people in a single Canadian sample having multiple conditions.^{18,22} The authors also demonstrate that multiple conditions exist in younger age groups, with a prevalence of 69% in 18-44 year olds, 93% in 45-64 year olds in a sample of Quebec family practices. Another article also identified that multiple conditions were a problem in younger adults.²³ These inconsistencies relate to not having access to consistent data. The problems associated with multiple conditions were identified as a greater likelihood of dying prematurely, more hospital admissions and longer hospital stays, a poorer quality of life including poor physical functioning, depression and all the associated problems of polypharmacy as well as interactions between treatment for one condition and treatments for other conditions.^{20,24}

Researchers interested in exploring these issues have been beset by problems of data collection. Current forms of disease classification and coding create barriers to the research and care of people with multiple conditions.²³ Disease coding may be variable while GP software is not helpful due to the different products and platforms that do not allow for sharing of data. Researchers in Germany undertook analyses of the health utilisation patterns of nearly 40,000 people with co-or multi-morbidities and consider that data structure is an essential means to build a basis to understand the needs and health utilisation of people with co-morbid or multiple conditions.²⁵

Data may not be valid. In Canada the problem with valid data on the extent of multi-morbidity in family practices in Canada continues to hold back research on its prevalence, allowing only estimates.¹⁸ By counting the number of conditions and using a severity rating scale the authors found that multiple conditions are more common in primary care than are single conditions. While the Charlson Co-morbidity Index (CCI) may be used to determine the association between medical co-morbidity and the number of tests for related conditions researchers concluded that more research was required to determine whether all patients with varying co-morbid illness burdens should receive equally aggressive care as it was difficult to determine if all equally benefited.²⁶ Application in Australia of the Cumulative Illness Rating Scale (CIRS) to Australian data drew comments on its limitations in comparing data from other studies.²¹

The problem of accurate definition

Problems of disease classification and data collection are interconnected with definitions and concepts. Firstly co-morbidity itself is not necessarily a simple term. A review that investigated the use of co-morbidity in health sciences literature from 1966 to 1994 pointed out the lack of consensus regarding the use of the concept.²⁷ Attempts to study the impact of co-morbidity are complicated by the

lack of consensus on how to define the concept, which leads to problems in measuring its impact.²⁸ The authors also note that co-morbidity and multi-morbidity may be used interchangeably. Following the influence of Feinstein's seminal definition, several studies have demonstrated that most studies between 1993 and 1997 investigated co-morbidity from the perspective of a specific or index disease, most commonly cardiovascular diseases (48%), cancers (23%), musculoskeletal diseases (13%), or diabetes (11%).^{27,29}

Secondly, while measuring co-morbidity has advanced our understanding, some authors conclude that the term *multi-morbidity*, defined by others as the 'co-occurrence of two or more diseases within one person, without defining an index-disease'²⁷ is a better means to study the complexity that is associated with having more than one condition.^{27,29}

Others have attempted definition of the terms multiple morbidities or multi-morbidities. Fortin et al³⁰ define multi-morbidity as multiple coexistent diseases; Mercer et al³¹ define multi-morbidity as the co-existence of two or more long-term conditions in an individual; Ritchie³² defines multi-morbidity as the 'simultaneous existence of more than one pathophysiological condition or clinical entity'; Min et al defines multi-morbidity as multiple coexisting chronic conditions³³.

Issues related to disease-specific guidelines

Where there are either co-morbidities or multiple conditions disease specific guidelines cause more problems than they solve, leading to adverse events, including drug interactions.¹⁹ Adherence to guidelines in patients with more than two chronic conditions may not be possible due to inconsistencies in recommendations across multiple diagnosed conditions.³⁴ Other arguments emphasise that it is no longer realistic to apply single disease guidelines to the care of people with multiple conditions as it does not leave enough time in primary care to care for all their needs.³⁵ At the same time, multi-morbidity exposes people to more adverse events, fragmentation of care and contradictory health care recommendations.³² In addition payment structures in the Australian health system as well as other health systems reinforce the commitment to single disease guidelines.²¹

Discussion

Problems of disease classification and data collection, which extend to the definition and terminology, were identified by workshop participants as pertinent to how their multiple conditions are managed. Regardless of whether conditions are co-morbid or multiple, conflicting definitions and lack of data influence the care of people. There are disagreements over how care is influenced by this conflict. For example, some research demonstrates

that multiple conditions are associated with poor outcomes, decreased quality of life, psychological distress, more frequent hospital admissions and longer stays, post-operative complications, higher cost of care and higher mortality³⁶. But the opposite viewpoint arises when others explored the time factors as well as numerous guidelines and concluded patients with greater multi-morbidity received better care than would be expected when based on the specific set of quality indicators they triggered.³³ Additionally other findings suggest that the quality of care increased as the number of conditions increased with little need to adjust for the difficulty of delivering the care.³⁷

Guidelines and evidence-based practice are based on single conditions constituting a barrier to care of multiple conditions.²⁴ The lack of articles on multi-morbidities and their diversity demonstrates an insufficient evidence-base for the care of people with multi-morbidities. Fortin who found that for every article on multi-morbidity there were 74 on asthma, 94 on hypertension and 38 on diabetes underscores this point.¹⁸

However in the workshop people with multiple conditions argued from their own experiences that they struggled to receive care coordinated between specialists, general practice (or family practice) and hospital care. Some argued that whilst they received good care for their index condition, another condition might be causing them greater concern. Often it was hard to find care for a co-morbid condition. Others pointed out that they personally had to ensure treatments they were offered would not interact with other treatments. It was important to have enough knowledge to be able to make decisions around 'trade-offs' in treatments where the benefits of treatment for one condition might interact with treatment for another condition.

One area of concern to workshop members that receives little attention in the literature on multi-morbidities relates to rare conditions. Although individual conditions may be rare in epidemiological terms (defined by the US Orphan Drugs Act as disease affecting less than 200,000 persons in the US or in Europe as one that affects less than five in 10,000) there are a great number of them.³⁸ The European Organisation for Rare Disease (EURORDIS) estimates there are between 5000 and 8000 rare conditions affecting as many as 30 million Europeans. Rare conditions may be terminal, chronic, progressive and disabling; many have genetic origins. Rare conditions may mean a person has difficulty receiving a correct diagnosis; delays in receiving a correct diagnosis may lead to complications, or lack of access to appropriate treatment including multidisciplinary care.³⁸ EURORDIS argues that the consequences of these difficulties and delays have hardly been researched, pointing to the problems that exist in data collection and classification of many rare conditions. At the same time and despite great advances in their care, rare conditions

often have complications related to treatment including side-effects of treatments and adverse effects from inappropriate treatment or inappropriately prescribed treatments. Treatments themselves may give rise to new conditions rather than simply giving rise to complications. For example, type 2 diabetes can occur in Thalassaemia and Cystic Fibrosis as a side effect of treatment.

Most rare conditions are the domain of specialist care, an outcome of the historical growth of care of single conditions, which compounds the poor coordination of care. However people with rare conditions see general practitioners as well. This might be for a range of reasons; treatment for a common cold; the renewal of a prescription or care of another condition. Lack of communication between specialists and generalists might cause inconvenience or pose a danger to the person's life.

Workshop participants, many of whom had rare conditions, had had direct experience of these issues. In some instances, participants were better informed about their condition and treatments than were the health professionals. Others such as people with type 1 diabetes had been provided incorrect treatment as persons with type 2 diabetes in emergency departments of large hospitals. Participants claimed it was far safer that they, or a family member, were in charge of coordinating their care than health professionals. In Griff's case he had 'interviewed' GPs before choosing someone who was willing to 'take the journey alongside him' and who respected his personal expertise in hemophilia. On the other hand Griff found that after developing Hepatitis C many of the health professionals he saw were more likely to focus on that condition than his other conditions, including the immediate reason for attending. It was also many years before his struggles with fatigue, poor motivation and lack of interest in life were identified as depression and he was treated for this. Part of Griff's recovery was self-administered through writing out his journey through illness towards a level of reconciliation with his lived experience.

Unfortunately for Griff and the consumers like him the research literature provided few suggestions on the health service reforms needed to better meet the needs of people with multiple conditions. However, those researchers who are aware of the problems that multi-morbidities create for health services as well as for those who live with them have a number of avenues to explore. Firstly and of greatest importance, research that addresses the shortcomings of funding the care of single conditions and promotes relevant reforms will drive changes. Issues related to safety of health care, especially with regard to adverse events related to polypharmacy, are also likely to drive research and reform. E-health is likely to provide pathways to enable health services to better grasp

relationships between conditions and treatment interactions.

Consumers in the workshop argued that their multiple conditions should be regarded as 'portfolios'. This portfolio approach would include specification of how each condition was interrelated. For example it would specify whether a condition was co-morbid, or iatrogenic or idiopathic. A portfolio could also build up individual guidelines that related to the combinations of each condition for that individual avoiding disease-specific guidelines and moving away from the perspective of the index condition if this were not applicable in a specific case.

Underlying any new approach is the need for new definitions and classifications related to multiple conditions.

Conclusions

People are now living longer with chronic conditions and are also developing new ones. Increasing age and survival rates are likely to lead to more conditions, which may be co-morbid or unrelated. Members of the Chronic Illness Alliance who attended a workshop on multiple conditions identified the need for new concepts to meet their health care needs. The needs they identified relate to polypharmacy, safety and quality issues related to adverse events, diagnosis, coordinated care including prioritising care and finally their own quality of life issues which includes the numerous stresses of living with multiple conditions.

While literature around multi-morbidities is largely concerned with problems arising in health services, many of the issues identified are equally of concern to people living with multi-morbidities. This literature identified the problems that create barriers to improving the system for the mutual benefit of health services and consumers. These problems are concerned with data collection and disease classification. As Feinstein noted with regard to accurate data collection on co-morbidities the need was to reflect the 'real world'. This would lead to better care of the whole person as well as a better understanding of patterns of mortality and morbidity. Feinstein's work provides a starting point for further research into multi-morbidities.

The continued conception of single disease guidelines and health funding systems that reimburse for the care of single conditions are major impediments to working effectively with people who have multiple conditions that cannot be assumed to fall under the umbrella term 'co-morbid'.

Fortunately for consumers, work in this area has begun, with a number of researchers recognising that care based on single diseases leads to continued barriers to full care as well as amplifying the risks of adverse events. Some researchers are considering the need to develop new definitions of multi-morbidity in recognition of the changing pattern of disease in the 21st century.

This literature review revealed that despite the consumer perspective being absent from the literature on multiple conditions, consumers and health service providers had similar concerns about the improvements that should be made to assist people with multiple conditions. The challenge represented by multiple conditions for both researchers and consumers with multi-morbidities is to redesign health systems and the way they are funded. Opportunities exist now to apply new innovations such as e-health applications to enhance communications and address poor coordination of all the services required by people with multiple conditions. It is the author's hope that this challenge will be met by health reformers and service providers partnering with consumers with multiple conditions so that innovations will eventually address consumers' needs with regard to delivering a safer, reflexive system of care that is affordable and works to provide people with multiple conditions with better quality of life beyond the health system, while at the same time delivering safer, better coordinated services with fewer unplanned hospital admissions. The first step is conceptualising multiple conditions.

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