

## **‘You say treatment, I say hard work’: treatment burden among people with chronic illness and their carers in Australia**

### **Abstract**

The aim of this study was to explore treatment burden among people with a variety of chronic conditions and comorbidities and their unpaid carers. The burden of living with ongoing chronic illness has been well established. However, the burden associated with proactively treating and managing chronic illness, commonly referred to as ‘treatment burden’, is less understood. This study helps bridge this gap in our understanding by providing an in-depth analysis of qualitative data collected from a large sample of adults from diverse backgrounds and with various chronic conditions. Using semi-structured in-depth interviews, data was collected with a large sample of 97 participants that included a high representation of people from culturally and linguistically diverse backgrounds and indigenous populations across four regions of Australia. Interviews were conducted during May to October 2012, either face-to-face ( $n = 49$ ) or via telephone ( $n = 48$ ) depending on the participant’s preference and location. Data was analysed using an iterative thematic approach and the constant comparison method. The findings revealed four interrelated components of treatment burden: financial burden, time and travel burden, medication burden and healthcare access burden. However, financial burden was the most problematic component with the cost of treatment being significant for most people. Financial burden had a detrimental impact on a person’s use of medication, but also exacerbated other types of burden such as access to healthcare services and the time and travel associated with treatment. The four components of treatment burden operated in a cyclical manner and although treatment burden was objective in some ways (number of medications, and time to access treatment), it was also a subjective experience. Overall, this study underscores the urgent need for healthcare professionals to identify patients overwhelmed by their treatment and develop ‘individualised’ treatment options to alleviate treatment burden.

**Keywords:** treatment burden; chronic illness; comorbidity; financial burden; carers

### **What is known about this topic?**

- Treatment burden refers to the consequences people experience as a result of undertaking treatment.
- Treatment burden can have severe consequences on the person, the healthcare system and the overall society.
- Healthcare professionals may lack the tools to detect people overwhelmed by adhering to complicated treatment routines, and hence lack the strategies to ease this burden.

### **What this paper adds?**

- The financial cost of treatment is the most concerning aspect of treatment burden, with the cost for treatment being significant for most people.
- Individualised treatment and innovative solutions are needed to reduce treatment burden among people with chronic illness and their carers.
- The findings offer a framework for health professionals to reduce this burden.

### **Introduction**

Chronic illness has become the epidemic of our times. Ongoing health conditions such as cardiovascular and respiratory illness, cancer and diabetes are currently the leading causes of morbidity and death (World Health Organization 2011). Chronic illness generally refers to an

illness that is prolonged in duration, does not often resolve spontaneously, is rarely cured completely and can be associated with functional impairment or disability (Australian Institute of Health and Welfare 2012). The increasing prevalence of chronic illness contributes to a significant burden on people, the healthcare system and society as a whole. Although the burden of illness is well defined, the burden associated with proactively treating and managing chronic illness, commonly referred to as ‘treatment burden’, is less understood.

Treatment burden is conceptually different from the burden of illness (May *et al.* 2009). Whereas the burden of illness represents the impact of chronic illness on a person, their family members and the healthcare system, treatment burden refers to the consequences they experience as a result of undertaking or engaging in treatment, such as medications, therapies, medical interventions, programs (Sav *et al.* 2012). A recent review conducted by Sav *et al.* (2013) indicated that treatment burden can be determined by numerous factors such as, personal characteristics (e.g., age and gender), illness duration/severity, treatment characteristics (e.g., number and dose of medications) and family circumstances (e.g., level of support).

Ironically, there is evidence that the healthcare system within which people receive treatment can contribute to treatment burden. Despite its purported aim to improve health and welfare, healthcare services can be characterised by burdensome features, such as poor coordination between healthcare professionals, poor health professional-patient relationships and a lack of adequate information (Eton *et al.* 2012, Moss & Crane 2010). Ineffective communication between healthcare professionals and patients about treatment can lead to confusion about treatment options and the initiation of unnecessary treatment (Moss & Crane 2010, Vijan *et al.* 2005). Paradoxically, as Eton *et al.* (2012) noted, a healthcare professional’s response to poor patient outcomes can be to intensify treatment, resulting in a more complex

treatment regimen ultimately leading to greater levels of burden. This additional burden can exacerbate the ‘work of being a patient’ (Tran *et al.* 2012, p. 2).

This negative cycle clearly indicates a need for healthcare professionals to be more sensitive to their patients’ preferences, explicitly weighing treatment burden against the potential benefits of treatment on an individual basis, in collaboration with the patient. However, from the perspective of healthcare professionals, there can be little appreciation of ‘the work’ associated with chronic illness management. Healthcare professionals can lack the tools to detect people overwhelmed by the ‘work’ of adhering to complicated treatment routines, and hence lack the strategies to ease this burden (May *et al.* 2009). If unaddressed, treatment burden can have severe consequences, including recurrence of illness, decline in health, reduced survival, and ineffective use of health resources (Brod *et al.* 2007, de Kraker *et al.* 2004, Moss & Crane 2010, Graves *et al.* 2007).

#### The present study

Although recent research has generally increased our understanding of the nature of treatment burden among people living with chronic illness (Bohlen *et al.* 2012, Gallacher *et al.* 2011), there are still significant gaps. Most research has focused on specific conditions, for example, diabetes, cancer, asthma and cystic fibrosis, rather than attempting to gain an overall understanding of the concept. While these conditions certainly impose intensive treatment demands and significant treatment burden on individuals, there is a need to understand the experiences of people with all types of complex chronic conditions and multiple comorbidities. Chronic illness rarely occurs in isolation, with most people who report having at least one chronic illness, also report having two or more conditions (Caughey *et al.* 2008). A lack of in-depth understanding among such people is problematic because the treatment burden

experiences of people with a particular illness (e.g., medication use for diabetes) may be significantly different from a person with multiple and complex health conditions.

Even in these specific populations, most of what we know about treatment burden is based on homogenous samples, in particular, elderly, Caucasian adults (e.g., Brod *et al.* 2007, Vijan *et al.* 2005). There is little emphasis on the experiences of those from culturally and linguistically diverse (CALD) populations, indigenous minority populations (Aboriginal and Torres Strait Islander) or those from economically and socially disadvantaged backgrounds. The experiences of diverse populations are important because at the most basic level, people from economically disadvantaged backgrounds are likely to report more financial burden due to out-of-pocket healthcare costs than those in full-time employment. People from cultural minority populations may also have unique issues, such as particular health beliefs, language barriers and discrimination, which may impact on their treatment burden experiences (Wilson *et al.* 2012). Finally, there is an absence of research on treatment burden from an unpaid carer's perspective, those who provide assistance with a number of daily activities without pay to people with chronic illness (McNamara & Rosenwax 2010). In addition to sharing some of the treatment burden with the person they are caring for, unpaid carers may also experience aspects of burden unique to the carer role (e.g., time, energy, etc.).

This study aims to address these gaps in knowledge by comprehensively exploring treatment burden among people with a variety of chronic conditions and comorbidities and from various backgrounds and their carers. The study contributes to our understanding of treatment burden by providing an in-depth analysis of qualitative data collected from a large sample of adults that included a high representation of people from culturally and linguistically diverse backgrounds and indigenous populations. The study focused on both common (e.g., diabetes) and unique chronic conditions (e.g., Peutz-Jeghers Syndrome) and drew knowledge

from both affluent and disadvantaged communities. To our knowledge, no such study has provided such an in-depth and comprehensive analysis of treatment burden.

## **Methods**

The study was guided by the interpretive social paradigm (Neuman 2010), based on the understanding that individuals construct their own reality and that knowledge is experienced in a social context. Given the focus on an in-depth understanding, an interpretive approach using qualitative methods was considered the most suitable study design.

### **Data collection**

Ethical approval for the study was obtained from the Human Research Ethics Committee of an Academic University (PHM/10/12/HREC). Semi-structured in-depth interviews were conducted with people with chronic illness and their carers. In-depth interviews were undertaken with 97 participants across four regions of Australia: Logan-Beaudesert, Mount Isa/North West region of Queensland, Northern Rivers area of New South Wales, and greater Perth area in Western Australia. These geographical regions were purposively selected as they represented considerable socioeconomic, cultural, geographical (e.g., metropolitan or rural/remote) diversity. Purposive snowball sampling techniques were used initially to locate participants via Reference Group contacts (key stakeholders and representatives from government and non-government organisations), their clients and networks. In addition, participants were recruited via pharmacies, general practices and other health care agencies and through other government and non-government organisations.

To participate in the study, participants needed to be: (a) either newly diagnosed (within six months) or have a chronic condition(s) for six months or more; or (b) were an unpaid carer for a person with a chronic condition. Prior to the in-depth interview, a short eligibility process

was conducted with each participant who expressed interest in the study to gather information about their health status, primary healthcare utilisation, demographics, condition/s status and duration. Eligible participants were then contacted for the in-depth interviews to be conducted.

## Procedure

An interview guide was developed, piloted and refined prior to the commencement of the in-depth interviews. A consumer researcher, who possessed the necessary life skills and experience, was appointed to ensure that data collection, data analysis and recommendations maintained a consumer focus. Probe questions included the extent and duration of illness, difficulties with medications, finances, relationships with healthcare professionals, and daily practical challenges.

Interviews were conducted personally by four members of the research team and transcribed verbatim upon completion. The location of and who conducted the interview was informed by the specific needs of the participant and consideration of their personal circumstances (e.g., age, gender and religious beliefs). The four interviewers were from different professional backgrounds (e.g., public health and healthcare professionals) and had different levels of research experience (senior researchers and investigators). To ensure interviewer consistency, verbal and written interview debriefs were sent to the entire research team by all interviewers throughout the data collection process and interviewers were trained on questioning.

Semi-structured, in-depth interviews were conducted during May to October 2012, either face-to-face ( $n = 49$ ) or via telephone ( $n = 48$ ), depending on the participant's preference and location. Interviews were audio-recorded and on average lasted 50 minutes. Several of the interviews with participants of CALD backgrounds were conducted with a bilingual interpreter upon the request of the participant. Interpreters were respected and trusted by each participant

and had well-established links with their relevant ethnic traditions and customs. Participants were advised that they could obtain a copy of the transcript if desired and were provided with a gift voucher as a token of appreciation for their time.

### Data analysis

Data collection and analysis were based on an integrated or cyclic, rather than a linear process, with each analysis set of data informing the collection of the following set. As soon as they were transcribed, each in-depth interview was analysed using an iterative thematic approach and the constant comparison method, which forms a key component of grounded theory analysis. Three researchers read and re-read the transcripts to familiarise themselves with the data and prepare for thematic analysis. These researchers used the electronic qualitative data analysis package QSR NVIVO 9© to assist with coding the data into themes and sub-themes. In accordance with the constant comparison method, the data was collected and analysed concurrently.

Although the initial coding of data was conducted by three researchers, to increase familiarisation with the data, the researchers did not code the interviews they personally conducted with each participant. The categories were then refined to form sub-themes and all themes and quotes were numbered in order to ensure the auditability of the analysis. Quotes were extracted to illustrate the themes were labelled to represent the source of data, for example, C represented consumer only, CA carer only, CC consumer and carer, IND indigenous person, (CALD) culturally and linguistically diverse background person, and CH consumer and healthcare professional.

Inter-rater reliability of the authenticity of coding (Carney *et al.* 1996) was conducted by another member of the research team randomly selecting samples of data. The data analysis process was also ‘subject to scrutiny and review’ (Bowen 2008) by the entire research team



and discussions were held throughout the analysis process. Data saturation with the whole data and subgroups, such as specific cultural groups or chronic conditions, was established when the participants' experiences and perspectives recurred in line with the themes identified in previously collected data. Given the diversity of the sample, it was not surprising that a large sample was required to reach saturation.

## **Results**

### **Sample demographics**

In total, 97 participants were interviewed. Table 1 highlights the demographic and medical characteristics of participants. The mean age of the participants was 57.2 years (range 16 to 83 years) and there were twice as many females as males. The majority of participants were consumers (with chronic illnesses) (71.1%). The most prevalent conditions were diabetes, respiratory, cardiovascular disease and musculoskeletal disorders. Additionally, the majority of participants (88.3%) had two or more comorbid conditions (e.g., bowel cancer, diabetes, and depression). Finally, participants experienced a range of different chronic conditions with cardiovascular illness being reported as the most prevalent, followed by other conditions (e.g., psoriasis, prolapsed bladder, premenstrual disorder, chronic fatigue etc.), and diabetes.

### **INSERT TABLE 1 HERE**

### **Treatment burden**

The following four themes were identified as representing treatment burden among people with chronic illness and their carers: financial burden, time and travel burden, medication burden, and healthcare access burden.

### *Financial burden*

The most widely discussed burden resulting from treatment of chronic illness, irrespective of participant background and chronic illness, was financial. Participants' described feeling concerned and worried about the financial aspect of their treatment. On most occasions, financial burden was instigated by the cost of medication and the cost of consultations with healthcare professionals:

... one medication alone is \$40 a month, another one is \$30 a month...that's \$70 a month over a period of 20 years - it's a lot of money [S2C\_1015]

Money spent obtaining treatment impacted negatively on family leisure and social/sporting activities, with one carer admitting feeling guilty about prioritising her son's medication needs over the broader social and recreational needs of her other children:

...we've had to completely stop any extracurricular [activities], they were doing dancing and swimming, and we've just had to say look guys, I'm sorry, but we just can't do anything, so nobody does anything, it's just all therapy. Which you know that upsets me. [S2CA\_1013]

Some participants, particularly those who had retired from paid employment, relied on their savings (e.g., superannuation) and resources provided by other family members to cope with the financial burden. Economically disadvantaged participants prioritised their medications according to cost and their capacity to pay. At times, they decided not to purchase medications that were not covered by pharmaceutical concession. This was particularly the

case for low-income earners and/or those without pharmaceutical concession benefits, such as a healthcare card:

...occasionally they say, 'could you try this', and you go to the chemist and its 40 bucks and then you think no I'll go without it. [S2C\_1023]

Private health insurance was partly seen as a solution to financial burden. An elderly woman with comorbidity said:

[without private health insurance], you'd be out in the middle of the dead less sea. [S2C\_004]

Although seen as a partial solution, private health insurance was a financial burden itself as it involved regular payments. Furthermore, even when private health insurance was available, the out-of-pocket expenses were sometimes unaffordable. One participant who had lost her eyesight and developed neuropathy in both legs because of diabetes complications admitted:

...tomorrow I'm going in to get ...[treatment] and I don't know how much we can claim back on that, it won't be very much and it costs \$200. [S2C\_1022]

The internal conflict created by the need for expensive private health insurance was evident in the statement of an elderly pensioner:

I live on vegemite sandwiches to keep my private health cover. [S2C\_1015]

As the above quote indicates, some participants felt that the current healthcare system left them with no choice but to obtain private health cover. Although the cost of treatment was problematic for low-income earners and pensioners, those in full-time paid employment also struggled. These participants described instances where they were absent from work for a number of days while receiving treatment, often losing income for this period. However, they did not qualify for government concessions (e.g., healthcare card), which added to the financial burden they experienced.

Aboriginal and Torres-Strait Islander participants were less troubled by the financial burden of treatment than participants of other cultural backgrounds. They attributed this to a newly established healthcare policy called 'Closing the Gap', which is an Australian Government initiative that subsidises medication for indigenous Australians (Australian Government Department of Human Services 2010). When asked to comment on this policy, one participant replied:

Absolutely it's been marvellous and even for my children. [SC2(IND)\_1011]

When asked to comment on the financial burden experienced prior to the introduction of the policy, another indigenous participant with cardiovascular illness replied:

Oh yes. It was [difficult] because you think to yourself. Now where am I going to get this \$60 to pay for this medication?...Sometimes I just didn't get it because I can't afford it. [S2C(IND)\_1159]

### *Time and travel burden*

Another common source of burden irrespective of gender, age or cultural background was the time required to access, administer and monitor treatment. The time investment necessitated by treatment on a daily basis was viewed by participants as relentless:

...there's always something that you have to do. Each week you either have to go to the dentist or podiatrist or go and get your pills from the chemist or, there's always something. [S2C\_1052]

Participants also complained about the amount of time they spent waiting to obtain treatment, particularly at healthcare clinics and private practices. Not surprisingly, many indicated that they would rather be doing activities they enjoyed. Time and travel burden was particularly problematic among participants with comorbidities. This was because these participants spent significant amounts of time attending healthcare clinics for the treatment of each of their conditions rather than receiving combined care. For example, one man who battled chronic asthma all his life and was recently diagnosed with diabetes and depression commented:

Last year it was a case of I might have six specialist appointments in a week, not doctors, specialists...Like I was seeing every man and his dog. [S2C\_1053]

Travel to and from primary and secondary health services to obtain treatment was also burdensome for carers, who often transported the person they cared for to and from such appointments:

..this is the carer's concern, 'cause I drop her off at the door but I want to walk her into where she's going, but I have to drop her off, then I go and circle around for ages looking for parking. [S2C(CALD)\_1124]

Travel burden appeared to be most problematic for participants in rural and remote locations. These participants were usually forced to travel to a metropolitan city to obtain treatment, sometimes three to four hours each way. For participants who participated in paid-employment, this type of travel was untenable and unsustainable:

You just didn't [access to healthcare specialists] because there were none available. I mean when you are working and you have two kids and your wife is working, you can't travel to...[metropolitan locations]. [S2CC(CALD)\_1038]

As outlined in the above quote, because of work commitments, participants in rural and remote areas found it difficult to access healthcare specialists located in metropolitan areas. Furthermore, working participants often used their holiday time to seek treatment or manage the symptoms of their illness. Some participants had made significant lifestyle changes to accommodate their illness, including relocating to smaller more accessible dwellings that were in closer proximity to treatment.

Finally, the time taken to learn about new treatments and ways to self-manage was particularly problematic for newly diagnosed participants. Participants spent significant time and effort learning and understanding their illness, managing symptoms and their prescribed medications, underscoring the 'hard work' associated with self-management of chronic illness.

### *Medication burden*

One of the key sources of treatment burden was associated with the use of medications. Medication burden resulted from side effects and adverse events from medication use, polypharmacy (multiple medication use), the inconvenience of organising medications and the stigma associated with taking medication.

Some participants described how they had experienced side-effects when using new medications. Weight gain/loss, sexual dysfunction, dizziness, nausea, hair loss, nightmares and dry mouth and throat were some of the problems experienced:

...it's affecting me sexually, and I'm not functioning because of the tablets so it's not a good thing. [S2C(CALD)\_1069]

The likelihood of side-effects was a major determinant of medication non-adherence among some participants. The side-effects associated with medication appeared to be indirectly related to the duration of a person's chronic conditions. This effect was the result of 'trial and error experiments' and participants learning to cope with the symptoms of their illness over time. Consequently, the presence of side-effects, or at least the impact of these on participants' lives, diminished as time passed.

Another source of medication burden derived from the need to take multiple medications and the inconvenience associated with organising and arranging those medications as exemplified by the following quote:

So, yeah it's annoying and it's always making sure that you've got them [medications] on hand...so you're always got your eye on the box to make sure that there's enough there. [S2C\_1026]

Some participants described the frustration they experienced about the inconvenience of having to rely on medication, especially when it interfered with daily activities, such as shopping and employment. Many participants also felt uncomfortable about their treatment, a finding that appeared to be related to the stigma associated with medication use and chronic illness. Male participants, particularly those from a CALD background, commented about how the use of medications reminded them of their illness. They often seemed troubled by the idea of having to rely on medications for the rest of their lives:

Medication, this means you are missing something, that's why they give you the medication. [S2C(CALD)\_1131]

Medication burden was further complicated by confusion about generic versus original-brand medicines, particularly for elderly participants. These participants seemed confused between the generic and the original-brand medications because of the physical similarities between them. Many participants insisted on purchasing original-brand medications only and as a result, they were paying higher prices for their medications, resulting in greater financial burden.

Although many participants discussed the burden associated with medication use, this was not the case for all participants. Regardless of the number and type of medications they were taking, a few participants seemed content with their use of medications. They discussed their medications in a positive manner; often praising the role they played in assisting them to manage their chronic conditions:

Yeah, oh hey, it [medication] saved my life, it gave me a life. [S2C\_1072]



Those who seemed to cope well with medication appeared to have learned effective methods over time as they experimented with different ways of managing their chronic illness and its treatment.

### *Healthcare access burden*

This type of burden resulted from either systemic healthcare obstacles or unhelpful professional-patient relationships. In relation to the systemic obstacles, a common complaint, particularly among those with low income and without private health insurance, was the waiting periods to obtain treatment:

We still are on the waiting list and nearly four years now, so she's used to it no.

[S2C(CALD)\_1125]

Much of the discussion around the burden of accessing healthcare was focused on the shortcomings of public healthcare services. Many of those who accessed such services complained about the lack of continuity they experienced when visiting healthcare professionals:

....the public health system. This frustrates me more than anything. When you get an appointment, go and see a specialist, every time you go back you see a different doctor. That is so frustrating. [S2CC\_1041]

Participants from a CALD background and/or those with special dietary practices discussed problems associated with the availability of adequate food options in some hospitals:

....the food, the halal food [food that is processed according to religious guidelines]... honestly, in the hospitals, it's a big problem. [S2C(CALD)\_1133]

However, in contrast to others, those of CALD background were less likely to discuss their frustrations with accessing healthcare services. These participants often expressed gratitude about living in Australia, especially when they compared their lives and health services in their native countries:

Nothing, I miss nothing. Medication for free, operation for free. If I stayed in Egypt as the same, as being there, I'd be died thirty years ago, maybe forty.  
[S2C(CALD)\_1131]

For participants of Aboriginal and Torres Strait Islander background, issues of structural racism were raised as being problematic. These were combined with culturally-specific health beliefs that influenced their willingness to use both primary and secondary health services, such as shame:

I think some of the barriers are that health services have been plain racist from my own experience and professionally I think every other culture is accepted except Aboriginal and Torres Strait Islander. [S2C(IND)\_1011]

The lack of collaboration between different healthcare professionals was also described as a source of burden. For example, a middle-aged woman with multiple chronic conditions,

including Hashimoto's thyroiditis (an autoimmune illness caused by an inflammation of the thyroid gland), commented:

It's [the health system] a bit disjointed, I guess, in that you put, you're in silos, you know...it's a bit sort of like, there's no coordination of a lot of it. [S2C\_1052]

The lack of collaboration between healthcare professionals occasionally resulted in contradictory advice about treatment. In some cases, this situation contributed to polypharmacy:

I don't know how many types of depression medicines she'd [healthcare professional] put me on.... After that episode and all that, I then went to another doctor which, in turn, he just wanted to give me another lot of tablets. [S2C(IND)\_1095]

The failure of some healthcare professionals, particularly GPs, to provide sufficient advice and information about treatment options was associated with treatment burden. Some participants spent large amounts of time trying to compensate for the lack of information by searching the internet or joining a consumer health organisation.

## **Discussion**

Of the four components of treatment burden outlined, financial burden emerged as the most problematic with the cost and out-of pocket expenses being significant for most people. Consequently, the financial burden of treatment is at the centre of the person's experience, as it not only had a detrimental impact on his/her use of medication, access to healthcare services

and time and travel associated with treatment, but also could be influenced by such matters. For example, it was possible for a person to delay treatment because of cost. On the other hand, travel associated with accessing healthcare resulted in financial strain, because of a lack of reimbursement for travel or loss of employment income. Additionally, treatment burden encompassed a cyclical aspect. For example, contradictory advice about treatment by healthcare professionals (healthcare access burden) could lead to polypharmacy (medication burden), which could then result in both a requirement for extra time to organise medications (time burden) and extra strain on financial resources (financial burden).

The findings corroborate existing research, underscoring the subjective and objective nature of treatment burden (Sav *et al.* 2013). Although treatment burden had an objective component, such as number of medications, and time to access to healthcare that was experienced by the majority of participants, it was also characterised by subjective experiences. These subjective experiences were determined by a person's conditions, level of complexity, duration, cultural background, age, gender and employment conditions. For example, although financial burden was less common in participants from Aboriginal and Torres Strait Islander background, these participants seemed more troubled by accessing healthcare services, mainly because of barriers such as discrimination. Similarly, while medication burden emerged as an important component of treatment burden, it was more problematic among people with certain conditions (e.g., diabetes and insulin use). Taken together, these findings underscore the need for 'individualised' approaches to alleviating treatment burden.

Ironically, the tasks of self-management, such as organising treatment and changing lifestyle, were identified as contributing to time or travel burden. Despite being hailed as a solution to the long-term management of chronic illness by healthcare providers and policy-makers, it is ironic that such self-management practices represent a significant burden for patients and their carers. Our findings align with a body of literature which suggests that burden

of self-management can be significant, underlining the notion of the ‘hard work’ of being a patient (Corbin & Strauss 1985, Gallacher *et al.* 2011). Our study has confirmed the important role this ‘work’ also plays in the treatment of chronic illness.

#### Implications for healthcare professionals

Healthcare professionals may be limited in their ability to address some of the treatment burden resulting from cost, which may require structural healthcare policy initiatives. Nevertheless, the voices of participants in this study have several implications for their role in alleviating the burden of treatment for their patients. Because of the subjective and objective nature of treatment burden, there is a need for healthcare professionals to implement ‘individualised’ treatment methods to alleviate its occurrence and impact. Healthcare professionals need to consider each person’s unique circumstances and preferences and offer consumer-directed holistic care that is responsive to their needs. Given that time and travel associated with obtaining treatment was a significant source of burden, it is also important that prescribed treatment tasks are kept to the minimum, which is necessary to minimise the ‘hard work’ of being a patient.

Healthcare professionals also need to identify patients overwhelmed by their treatment regimen and openly discuss treatment burden issues with such patients. However, because treatment burden is a relatively new concept for healthcare professionals (May *et al.* 2009), in-depth discussions about this issue may not be viable. We agree with Bohlen *et al.*’s (2012) comments, arguing that healthcare professionals may need education strategies for this health issue. Although education strategies may assist patients and professionals to discuss treatment burden with effect, the constraints faced by healthcare professionals (e.g., short consultation times) may obscure their ability to identify and help burdened patients. Another alternative would be to increase collaboration between healthcare professionals and consumer health

organisations (e.g., American Diabetes Association), who can provide educational resources, skills training, self-management, and support services (Sav *et al.* 2012). By participating in such organisations, patients may be able to create avenues for experiential learning and a sense of belonging and opportunities for social engagement, which may be difficult to obtain from a healthcare professional (Boyle *et al.* 2009, Sav *et al.* 2012).

Finally, there is a need for greater coordinated care between healthcare professionals, particularly for the high proportion of individuals with comorbidities who often have to visit multiple healthcare services for treatment. Our findings confirmed that fragmented care can not only lead to time and travel burden for people but also result in contradictory advice about treatment. Coordinated care between healthcare professionals is not straightforward and evidence indicates that it is a complex process, has a number of components and occurs at different levels (Ehrlich *et al.* 2009). However, some patients may only require certain components of coordinated care, such as effective communication and information sharing between healthcare professionals, and these components may suffice to make a positive impact in alleviating treatment burden. Hence, healthcare professionals need to assess which components of coordinated care are essential for mitigating treatment burden among specific individuals, underscoring the need for individualised treatment.

### Limitations

Our study used qualitative research methods to explore the experiences of participants at one point in time, and hence, the complex relationships among themes cannot be established. In addition, we relied on self-reported data that can be influenced by interviewer and participant bias. However, the potential for interviewer bias arising from different interviewers was minimised by using a standardised interview framework to guide data collection and analysis. Because treatment burden contains subjective components, it would be interesting to examine

treatment burden among people using longitudinal data, which would enable a more comprehensive understanding regarding its dynamic nature. Despite its large diverse sample, we recognise that the views expressed by participants in this study may not be generalisable. However, the purpose of qualitative research is to obtain rich and holistic information about a phenomenon of interest from relevant stakeholders, an objective which we believe we have achieved.

## **Conclusion**

The experiences of people with chronic illness and their carers in this study can form a useful framework for healthcare professionals who wish to help plan in the words of May *et al.* (2009), ‘minimally disruptive medicine’ for their patients. Clearly, the burden of treatment for chronic illness is a significant issue and will become even more compounded with the projected rise of chronic illness in Australia and around the world. The financial burden of treatment in particular should not be underestimated. There is an urgent need for identifying overwhelmed patients and to develop ‘individualised’ treatment options, as well as innovative solutions that challenge the current paradigm of health care.

## References

- Australian Government Department of Human Services (2010). *Closing the Gap - Pharmaceutical Benefits Scheme Co-payment Measure*. [WWW document]. URL <http://www.medicareaustralia.gov.au/provider/pbs/prescriber/closing-the-gap.jsp> (accessed on 08/11/2012).
- Australian Institute of Health and Welfare (2012) *Chronic Disease*. [WWW document]. URL <http://www.health.gov.au/internet/main/publishing.nsf/content/chronic> (accessed on 25/11/2012).
- Bohlen K., Scoville E., Shippee N.D., May C.R. & Montori V.M. (2012) Overwhelmed Patients: A videographic analysis of how patients with type 2 diabetes and clinicians articulate and address treatment burden during clinical encounters. *Diabetes Care*, **35** (1), 47-49.
- Boyle F.M., Mutch A.J., Dean H.J., Marie-Louise D. & Del Mar C. (2009) Consumer health organisations for people with diabetes and arthritis: who contacts them and why? *Health and Social Care in the Community* **17** (6), 628-635.
- Bowen G.A. (2008). Naturalistic inquiry and the saturation concept: a research note. *Qualitative Research* **8** (1), 137-152.
- Brod M., Christensen T. & Bushnell D. (2007) Maximizing the value of validation findings to better understand treatment satisfaction issues for diabetes. *Quality of Life Research* **16** (6), 1053-1063.
- Carney O., McIntosh J. & Worth A. (1996) The use of the Nominal Group Technique in research with community nurses. *Journal of Advanced Nursing* **23** (5), 1024-1029.
- Caughey G., Vitry A., Gilbert A. & Roughead E. (2008) Prevalence of comorbidity of chronic diseases in Australia. *BioMed Central Public Health* **8** (1), 221.



- Corbin J. & Strauss A. (1985) Managing chronic illness at home: three lines of work. *Qualitative Sociology* **8** (3), 224-247.
- De Kraker J., Graf N., Van Tinteren H., Pein F., Sandstedt B., Godzinski J. & Tournade M.F. (2004) Reduction of postoperative chemotherapy in children with stage I intermediate-risk and anaplastic Wilms' tumour (SIOP 93-01 trial): a randomised controlled trial. *Lancet* **364**, 1229-1235.
- Ehrlich C., Kendall E., Muenchberger H. & Armstrong K. (2009) Coordinated care: what does that really mean? *Health & Social Care in the Community* **17** (6), 619-627.
- Eton D.T., Oliveira O.R., Egginton J.S., Odell L., May C.R. & Montori V.M. (2012) Building a measurement framework of burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient Related Outcome Measures* **3**, 39-49.
- Gallacher K., May C.R., Montori V.M. & Mair F.S. (2011) Understanding patients' experiences of treatment burden in chronic heart failure using normalization process theory. *Annals of Family Medicine* **9** (3), 235-243.
- Graves M.M., Adams C.D., Bender J.A., Simon S. & Portnoy J.M. (2007) Volitional nonadherence in pediatric asthma: parental report of motivating factors. *Current Allergy and Asthma Reports* **7** (6), 427-432.
- May C., Montori V.M. & Mair F.S. (2009) We need minimally disruptive medicine. *British Medical Journal* **339**, 485-487.
- McNamara B. & Rosenwax L. (2010) Which carers of family members at the end of life need more support from health services and why? *Social Science & Medicine* **70** (7), 1035-1041.
- Moss L. & Crane P.B. (2010) Exploring polypharmacy in elderly women after myocardial infarction. *Journal of Women and Aging* **22** (1), 22-33.

- Neuman W.L. (2010). *Social Research Methods: Qualitative and Quantitative Approaches*, 7th edn. Pearson Education, Boston.
- Sav A., McMillan S.S., Kelly F., Kendall E., Whitty J.A., King M.A. & Wheeler A.J. (2012) Treatment burden among people with chronic illness: what are consumer health organizations saying? *Chronic Illness*. doi: 10.1177/1742395312463411
- Sav A., King M.A., Whitty J.A., Kendall E., McMillan S.S., Kelly F., Hunter B., & Wheeler A.J. (2013). Treatment burden in chronic illness: a concept analysis and review of the literature. *Health Expectations*. doi: 10.1111/hex.12046
- Tran Q.V., Montori V.M., Eton D.T., Baruch D., Falissard B. & Ravaud P. (2012) Development and description of measurement properties of an instrument to assess treatment burden among patients with multiple chronic conditions. *BioMed Central Medicine* **10** (68), 1-10.
- Vijan S., Hayward R.A., Ronis D.L. & Hofer T.P. (2005) Brief report: the burden of diabetes therapy: Implications for the design of effective patient-centered treatment regimens. *Journal of General Internal Medicine* **20** (5), 479-482.
- Wilson C., Alam R., Latif S., Knighting K., Williamson S. & Beaver K. (2012) Patient access to healthcare services and optimisation of self-management for ethnic minority populations living with diabetes: a systematic review. *Health and Social Care in the Community* **20** (1), 1-19.
- World Health Organization (2011) *Noncommunicable Diseases Country Profiles 2011*. Geneva, Switzerland. [WWW document]. URL [http://whqlibdoc.who.int/publications/2011/9789241502283\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789241502283_eng.pdf) (accessed on 15/04/2012).