

## News Media Representations of Responsibility for Alcohol-Related Liver Disease Requiring Liver Transplantation

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### Résumé de l'article

Les maladies hépatiques liées à l'alcool (MHLA) sont une indication courante pour la transplantation du foie, mais elles sont considérées comme éthiquement controversées dans les discours universitaires, cliniques et publics. Divers groupes sociaux considèrent les personnes atteintes d'une MHLA comme personnellement responsables de leur état et se demandent alors si elles devraient avoir accès à une ressource rare. La manière dont les médias d'information établissent la responsabilité de la MHLA peut influencer l'opinion publique à l'égard des personnes malades ainsi que les politiques de santé qui s'y rapportent. Étant donné que le système de transplantation d'organes repose sur la volonté des individus à donner leurs organes, comprendre comment les médias présentent les questions controversées est une question d'importance vitale pour la santé publique et les politiques de santé. Nous avons donc étudié la manière dont la responsabilité des personnes souffrant de MHLA nécessitant une transplantation de foie est présentée au grand public dans les médias d'information. En utilisant une recherche par mot-clé dans deux bases de données d'information en ligne, nous avons sélectionné 81 articles du Royaume-Uni, du Canada et des États-Unis. Nous avons analysé les articles en utilisant une approche psychologique discursive. Notre analyse révèle que les médias d'information attribuent la responsabilité des MHLA à trois acteurs principaux : les individus ayant une MHLA, les prédispositions biologiques et les représentants des politiques et de l'industrie. Elle révèle également que la manière dont la responsabilité des MHLA nécessitant une transplantation de foie est présentée dans les médias peut avoir des implications pour les personnes diagnostiquées avec d'autres troubles liés à la consommation qui se présentent pour une candidature à une transplantation ou qui sont sur la liste d'attente de transplantation. Enfin, cette étude peut aussi nous donner une idée sur la manière dont le concept de responsabilité est compris pour d'autres maladies stigmatisées ainsi que ses implications potentielles sur l'équité en matière de santé des populations.



ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

# News Media Representations of Responsibility for Alcohol-Related Liver Disease Requiring Liver Transplantation

Kristie Serota<sup>a,b</sup>, Grace Bannerman<sup>c,d</sup>, Rachel Hong<sup>a,c</sup>, Daniel Z Buchman<sup>a,b,e,f</sup>

## Résumé

Les maladies hépatiques liées à l'alcool (MHLA) sont une indication courante pour la transplantation du foie, mais elles sont considérées comme éthiquement controversées dans les discours universitaires, cliniques et publics. Divers groupes sociaux considèrent les personnes atteintes d'une MHLA comme personnellement responsables de leur état et se demandent alors si elles devraient avoir accès à une ressource rare. La manière dont les médias d'information établissent la responsabilité de la MHLA peut influencer l'opinion publique à l'égard des personnes malades ainsi que les politiques de santé qui s'y rapportent. Étant donné que le système de transplantation d'organes repose sur la volonté des individus à donner leurs organes, comprendre comment les médias présentent les questions controversées est une question d'importance vitale pour la santé publique et les politiques de santé. Nous avons donc étudié la manière dont la responsabilité des personnes souffrant de MHLA nécessitant une transplantation de foie est présentée au grand public dans les médias d'information. En utilisant une recherche par mot-clé dans deux bases de données d'information en ligne, nous avons sélectionné 81 articles du Royaume-Uni, du Canada et des États-Unis. Nous avons analysé les articles en utilisant une approche psychologique discursive. Notre analyse révèle que les médias d'information attribuent la responsabilité des MHLA à trois acteurs principaux : les individus ayant une MHLA, les prédispositions biologiques et les représentants des politiques et de l'industrie. Elle révèle également que la manière dont la responsabilité des MHLA nécessitant une transplantation de foie est présentée dans les médias peut avoir des implications pour les personnes diagnostiquées avec d'autres troubles liés à la consommation qui se présentent pour une candidature à une transplantation ou qui sont sur la liste d'attente de transplantation. Enfin, cette étude peut aussi nous donner une idée sur la manière dont le concept de responsabilité est compris pour d'autres maladies stigmatisées ainsi que ses implications potentielles sur l'équité en matière de santé des populations.

## Mots-clés

maladie du foie liée à l'alcool, transplantation du foie, responsabilité, analyse des médias, bioéthique, stigmatisation

## Abstract

Alcohol-related liver disease (ARLD) is a common indication for liver transplantation yet it is considered ethically controversial in academic, clinical and public discourses. Various social groups consider people with ARLD as personally responsible for their condition and question whether they should have access to a scarce resource. How the news media constructs responsibility for ARLD may influence public opinions toward those who are ill as well as related healthcare policies. Since the organ transplantation system relies on the willingness of individuals to donate organs, understanding how the media portrays controversial issues is a matter of vital importance for public health and health policy. We investigated how responsibility for ARLD requiring liver transplantation is presented for public consumption in the news media. Using a keyword search of two online news databases, we selected 81 articles from the United Kingdom, Canada and the United States. We analyzed the articles using a discursive psychological approach. We found that the news media ascribed responsibility for ARLD to three main actors: individuals with ARLD, biological predisposition, and policy and industry representatives. How responsibility for ARLD requiring liver transplantation is presented in the news media may have implications for people diagnosed with other substance-related disorders who present for transplant candidacy or are on the transplant waiting list. Investigating how responsibility for ARLD is constructed in news media may provide insights into how responsibility is understood in other stigmatized health conditions and its potential implications for population health equity.

## Keywords

alcohol related liver disease, liver transplantation, responsibility, media analysis, bioethics, stigma

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## INTRODUCTION

Alcohol-related liver disease (ARLD) is a common indication for liver transplantation in North America and the United Kingdom. In Canada, ARLD is the second most common reason for receiving a liver transplantation, following Hepatitis C (1). Liver transplantation for ARLD is considered ethically controversial because a solid organ for transplantation is an absolutely scarce resource: the demand exceeds the supply. Debates over what criteria should be used to determine how this resource should

be allocated and to whom have garnered much critical attention both within the academy and in various medias (2). Some scholars argue that ARLD is a self-inflicted condition for which patients are personally responsible, and this personal responsibility justifies allowing some individuals lesser claim to scarce medical resources (3,4). However, others argue that basing resource claims on responsibility undermines the patient-clinician relationship and the very functioning of medicine itself (5).

This debate led to the creation of the “six-month abstinence rule” in the majority of transplant centres worldwide, which stipulates patients must remain abstinent from alcohol for six months before being placed on the transplant list (6). Supporters of the six-month rule argue that an abstinence period may result in hepatic recovery, such that a transplant is no longer necessary, and that it should reduce the risk of relapse post-transplant. Critics argue that the six-month rule is not supported by scientific evidence. In a meta-analysis of transplant outcomes, Dew and colleagues describe the empirical evidence supporting the six-month rule as “sparse and contradictory”; additionally, there is a weak correlation between the six-month rule and post-transplant alcohol relapse (7). A group of Canadian researchers have argued that the six-month rule is a restrictive barrier to treatment for two groups of patients, those with acute alcohol-related hepatitis, and patients with end-stage cirrhosis who may not survive six-months without treatment (6). Recent studies in the United States and Europe have demonstrated survival rates post-transplant similar to patients who received a liver transplant for other indications as well as low rates of return to drinking (8,11,17). The abstinence rule bars patients in both of these groups from accessing a potentially life-saving liver transplant. Given the lack of scientific evidence that supports the six-month rule, and the number of patients who may benefit from a transplant, other scholars have argued that the six month rule is ethically indefensible. In particular, these authors argue that requiring a patient to take personal responsibility for their health is not a requirement to access treatment in other areas of healthcare (9-12).

Media representations of health and illness can influence how members of the public view people who are ill (13). In particular, the news media functions as a source of public information on various substance use disorders, with journalists continually influencing perspectives and debates (14). Indeed, the news media plays an instrumental role in creating and perpetuating health-related stigmas through moralizing descriptions of certain behaviours as good and bad (14,15). How the news media constructs moral concepts such as responsibility and what one is owed as a result may influence public opinions and acceptance for policy decisions related to ARLD. In this article, we analyse how the news media constructs responsibility for ARLD requiring liver transplantation in Canada, the United Kingdom, and the United States. We explore ways in which the concept of responsibility might provide insight into societal moral attitudes toward people who use alcohol and the claims they might make to scarce health-related resources. We employ discursive analysis to investigate who is positioned as the responsible agent in the news article and what they are described as being responsible for (see Theoretical and Methodological Framework below). We believe that understanding how moral concepts such as responsibility are portrayed in the news media is especially important in light of recent research and policy decisions that suggest abandoning the six-month abstinence rule for ARLD requiring liver transplantation (16,17).

## RESPONSIBILITY AND ORGAN TRANSPLANTATION

Responsibility is a common theme in academic discussions about health and disease, particularly around substance use and transplant eligibility. A recent scoping review on ethics, substance use, and transplantation found a disproportionate emphasis in the peer-reviewed literature on personal responsibility (18). Glannon has argued that “the more control one has over one’s health, the more responsible one is for a diseased condition” (3, p.33). From this perspective, responsibility for maintaining health and avoiding disease is a matter of degree based upon one’s capacity for control. Moral responsibility, according to Glannon, is based upon causal responsibility (19). A person is causally responsible for their liver disease if their alcohol consumption is voluntary, and they have the capacity to know that this action may carry the risk of liver disease. A person is morally responsible if they are causally responsible and “negligent for failing to act on the knowledge that chronic drinking can lead to [ARLD] and increased competition for scarce transplantable livers” (19, p.25). Glannon argues that because donated livers are an absolutely scarce resource, if a person is morally responsible for ARLD they can justifiably be given lower priority for a transplant than someone who is not responsible for their disease (3,4,19).

Other scholars argue that morality and responsibility should not be relevant to decisions about the allocation of scarce medical resources (5). Anderson and Nielson argue that the causal approach to responsibility in fact leads to the opposite conclusion to Glannon (3,19,20). Based on evidence that biological, environmental and social factors influence the distribution and risk of diseases, they conclude that personal or moral responsibility for diseases related to alcohol consumption is impossible. Increasingly, addictions to substances such as alcohol are considered chronic, relapsing brain diseases, such that the person does not necessarily have ‘control’ over their consumption and so should not be held responsible (21). Levy argues that capacities for responsibility and the circumstances in which one is able to enact their responsibilities (considering the social determinants of health) is a matter of distributive justice – not all people are able to take responsibility for their own health (22). Based on these perspectives, substance use leading to poor health is not based on personal choice entirely; they may be beyond one’s capacity for control and consideration should be given to the (inequitable) conditions in which responsibility for health is expected. And so, “we cannot justify any differential health care treatment – or differential treatment in general – by independent appeals to responsibility” (20, p.483). Further, technically determining causal moral responsibility in practice is a very difficult if not impossible task (5,23).

## MEDIA REPRESENTATIONS OF SUBSTANCE USE, ADDICTION, AND ORGAN DONATION

Various forms of media can influence what information regarding health and illness is disseminated to publics and how it is presented. The news media functions as a source of public information on various addictions, with journalists continually influencing perspectives and debates (13). Thus, the media may shape public opinion, reactions and acceptance for various health related policies and procedures (21-25).

In a study examining news media portrayals of addiction across 14 countries – including Canada, the United States, and the United Kingdom – Robillard and Illes found that media reports often link addictions to criminal responsibility, thereby reifying a common stereotype of the criminalized other (29). These authors argue that presenting people with addictions as criminals perpetuates stigmatizing notions of mental illness. Further, these stigmatizing portrayals may impact public perceptions of addiction and mental illness, how US courts address these issues, and how public health authorities employ health promotion strategies. Aspler and colleagues explored how information about fetal alcohol spectrum disorder (FASD) is presented in the Canadian print media and found evidence of “ethically consequential exaggeration” about FASD and women’s alcohol consumption, and particularly how it is represented in Indigenous communities (30). In another international study of addiction discourses in news media, Bujalski and colleagues suggest that from 1991 to 2011 the media in Finland, Italy and Poland increasingly presented issues related to substance use in two ways: in terms of scientific advancements and from the perspective of individualism (14). Hellman identified a similar trend of increasing individualization in addiction discourses in Finnish media articles across four decades. Instead of presenting addiction as a social or political issue, the media frames it increasingly as a physiological issue requiring medical expertise and treatment (14,31).

The media may also affect public beliefs about organ donation and transplantation. Supporters of organ donation have found that messages supporting donor registration compete against misinformation presented in the entertainment media (32-35). Morgan and colleagues suggest that inaccurate portrayals in the US media result in misguided societal beliefs about organ donation and may influence individual’s decisions to opt against becoming a donor (34). For example, this misinformation includes portrayals of a black market of stolen organs, morally corrupt transplant surgeons and untrustworthy organ allocation systems. Some transplantation specialists have accused negative media representations of transplantation for contributing to changing public attitudes towards organ donation (34,36-38). Morgan and colleagues argue that the donation myths perpetuated in the media should be replaced by “entertainment education” which is a health promotion technique that aims to improve public understanding of health behaviours (39).

If the media influences public opinions and acceptance of policies related to health and illness, then it is necessary to investigate media portrayals of ARLD to understand how responsibility is constructed and where responsibility is located. Since the organ transplantation system relies upon the willingness of individuals to donate organs after death, or in some situations as a living donor, understanding how public attitudes are shaped in this regard is a matter of vital importance for public health and health policy. Currently, however, the way that responsibility for ARLD and liver transplants is described in the news media is unknown.

## METHOD

### Data Collection

We conducted a keyword search of two online newspaper databases: Factiva and Canadian Newsstand (Table 1). We assessed for inclusion English-language articles of 50 or more words published between January 1, 2011 and July 18, 2016 from Canada, the United Kingdom, and the United States. We chose these three English-speaking countries to sample from diverse contexts with different healthcare systems, encompassing a mix of private and public systems. Additionally, each of these countries has a high rate of liver disease requiring transplantation, accounting for approximately 15-30% of transplant cases in each country (1,36,37). We identified 5,213 articles through the keyword search. We included in our final data set articles in which alcohol use is described as a factor that may lead, or has led, to the need for a liver transplant. This resulted in eighty-one articles, which included 52 from the United Kingdom, 22 from Canada, and 7 from the United States (Figure 1).

**Table 1. Detailed breakdown of search parameters and terms**

| Parameter                                              | Factiva |                                 | Canadian Newsstand |                             |
|--------------------------------------------------------|---------|---------------------------------|--------------------|-----------------------------|
| Date                                                   | Date    | 01/01/2011 to 19/07/2016        | Date               | Date: After January 01 2011 |
| Include only articles published in Canada, USA, and UK | Text    | (rst=cana or rst=usa or rst=uk) |                    |                             |
|                                                        | Region  | All Regions                     |                    |                             |

|                      |              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                 |                     |
|----------------------|--------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------|---------------------|
|                      | Source       | Not Africa, Not Asia, Not Australia/Oceania, Not Caribbean Islands, Not Central America, Not CIS Countries, Not Latin America, Not Mediterranean, Not Middle East, Not South America, Not Central/Eastern Europe, Not Greece, Not Nordic Countries, Not Andorra, Not Austria, Not Belgium, Not France, Not Germany, Not Ireland, Not Italy, Not Liechtenstein, Not Luxembourg, Not Malta, Not Monaco, Not Netherlands, Not Portugal, Not San Marino, Not Spain, Not Switzerland, Not Vatican City, Not Bermuda, Not Greenland, Not Mexico, Not St. Pierre and Miquelon |                 |                     |
| Language             | Text         | rst=en                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | Language        | English             |
|                      | Language     | English                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                 |                     |
|                      | Source       | Not Arabic, Not Bahasa Indonesia, Not Bahasa Melayu, Not Bulgarian, Not Catalan, Not Chinese (simplified), Not Chinese (traditional), Not Czech, Not Danish, Not Dutch, Not Finnish, Not French, Not German, Not Hungarian, Not Italian, Not Japanese, Not Korean, Not Norwegian, Not Polish, Not Portuguese, Not Russian, Not Slovak, Not Spanish, Not Swedish, Not Thai, Not Turkish, Not Vietnamese                                                                                                                                                                 |                 |                     |
| Any author           | Author       | All Authors                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |                 |                     |
| Any news agency      | Company      | All Companies                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | Exclusions      | [Left blank]        |
| News article format  | Subject      | Not Advertorials, Not Advice, Not Audio-visual Links, Not Blogs, Not Calendar of Events, Not Headline Listings, Not Headline-Only Content, Not Images, Not Letters, Not Obituaries, Not Personal Announcements, Not Prospectuses, Not Reviews, Not Routine General News, Not Routine Market/Financial News, Not Transcripts                                                                                                                                                                                                                                            |                 |                     |
|                      | Source       | Not All Blogs, Not All Pictures, Not All Multimedia, Not Press Release Wires, Not Reuters Newswires. Not A-list Blogs, Not Business to Consumer Services (B2C), Not Magazines and Journals, Not Official Government Sources, Not Trade (B2B), Not Transcripts: All, Not Wires                                                                                                                                                                                                                                                                                          | Source type:    | Newspapers, Reports |
|                      | News Filters | Sources: Not NewsRx Medical Newsletters - All sources, Not Chemicals & Chemistry, Not British Medical Journal (Abstracts), Not Politics & Government Week, Not Examiner                                                                                                                                                                                                                                                                                                                                                                                                |                 |                     |
| Appropriate industry | Industry     | All Industries                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                 |                     |
| Length               | Text         | wc>50                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Text            | WC(>50)             |
|                      |              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Full text (Y/N) | No                  |

|                                                                                             |                         |                                                                       |      |                                                                                                                                                                                                                                         |
|---------------------------------------------------------------------------------------------|-------------------------|-----------------------------------------------------------------------|------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Concept: alcohol use                                                                        | Text                    | (atleast2(alcohol*) or atleast2(drink*))                              |      | (alcohol* OR drink*)<br><br>After receiving results, researcher manually applied the parameter for requiring at least 2 mentions of "alcohol*" or at least 2 mentions of "drink*" by scanning the titles and abstracts of the articles. |
| Concept: transplantation                                                                    |                         | (transplant*) and (hlp=transplant*)                                   |      | transplant* AND (ab(transplant*) OR ti(transplant*))                                                                                                                                                                                    |
| Concept: liver                                                                              |                         | (liver\$3)and (hlp=liver\$3)                                          |      | liver[*3] AND (ab(liver[*3]) OR ti(liver[*3]))                                                                                                                                                                                          |
| Concept importance: search headline and lead paragraph or [news] article abstract           | Text                    | (hlp=alcohol* or hlp=drink*) and (hlp=transplant*) and (hlp=liver\$3) | Text | (ab(transplant*) OR ti(transplant*)) AND (ab(liver[*3]) OR ti(liver[*3])) AND ((ab(alcohol*) OR ti(alcohol*)) OR (ab(drink*) OR ti(drink*)))                                                                                            |
| Including identical articles reprinted in different publications across Canada, USA, and UK | Reject republished news | Off                                                                   |      |                                                                                                                                                                                                                                         |

| Factiva |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Canadian Newsstand |                                                                                                                                                                                                                   |
|---------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Text    | rst=en and (liver\$3) and (transplant*) and (atleast2(alcohol*) or atleast2(drink*)) and (rst=cana or rst=usa or rst=uk) and (hlp=alcohol* or hlp=drink*) and (hlp=transplant*) and (hlp=liver\$3) and wc>50                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Text               | ((alcohol* OR drink*) AND transplant* AND liver[*3] AND WC(>50)) AND (ab(transplant*) OR ti(transplant*)) AND (ab(liver[*3]) OR ti(liver[*3])) AND ((ab(alcohol*) OR ti(alcohol*)) OR (ab(drink*) OR ti(drink*))) |
| Date    | 01/01/2011 to 19/07/2016                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | Date               | Date: After January 01 2011                                                                                                                                                                                       |
| Source  | Not Arabic, Not Bahasa Indonesia, Not Bahasa Melayu, Not Bulgarian, Not Catalan, Not Chinese (simplified), Not Chinese (traditional), Not Czech, Not Danish, Not Dutch, Not Finnish, Not French, Not German, Not Hungarian, Not Italian, Not Japanese, Not Korean, Not Norwegian, Not Polish, Not Portuguese, Not Russian, Not Slovak, Not Spanish, Not Swedish, Not Thai, Not Turkish, Not Vietnamese, Not Africa, Not Asia, Not Australia/Oceania, Not Caribbean Islands, Not Central America, Not CIS Countries, Not Latin America, Not Mediterranean, Not Middle East, Not South America, Not Central/Eastern Europe, Not Greece, Not Nordic Countries, Not Andorra, Not Austria, Not Belgium, Not France, Not Germany, Not Ireland, Not Italy, Not Liechtenstein, Not Luxembourg, Not Malta, Not Monaco, Not Netherlands, Not Portugal, Not San Marino, Not Spain, Not Switzerland, Not Vatican City, Not Bermuda, Not Greenland, Not Mexico, Not St. Pierre and Miquelon, Not All Blogs, Not All Pictures, Not All Multimedia, Not Press Release Wires, Not Reuters Newswires, Not A-list Blogs, Not Business to Consumer Services (B2C), Not Magazines and Journals, Not Official Government Sources, Not Trade (B2B), Not Transcripts: All, Not Wires | Source type:       | Newspapers, Reports                                                                                                                                                                                               |

|                         |                                                                                                                                                                                                                                                                                                                             |                |         |
|-------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------|---------|
| Author                  | All Authors                                                                                                                                                                                                                                                                                                                 |                |         |
| Company                 | All Companies                                                                                                                                                                                                                                                                                                               | Exclusions     |         |
| Subject                 | Not Advertorials, Not Advice, Not Audio-visual Links, Not Blogs, Not Calendar of Events, Not Headline Listings, Not Headline-Only Content, Not Images, Not Letters, Not Obituaries, Not Personal Announcements, Not Prospectuses, Not Reviews, Not Routine General News, Not Routine Market/Financial News, Not Transcripts | Fulltext (Y/N) | No      |
| Industry                | All Industries                                                                                                                                                                                                                                                                                                              |                |         |
| Region                  | All Regions                                                                                                                                                                                                                                                                                                                 |                |         |
| Language                | English                                                                                                                                                                                                                                                                                                                     | Language       | English |
| News Filters            | Sources: Not NewsRx Medical Newsletters - All sources, Not Chemicals & Chemistry, Not British Medical Journal (Abstracts), Not Politics & Government Week, Not Examiner                                                                                                                                                     |                |         |
| Reject unpublished news | Off                                                                                                                                                                                                                                                                                                                         |                |         |
| Timestamp               |                                                                                                                                                                                                                                                                                                                             |                |         |

## Theoretical and Methodological Framework

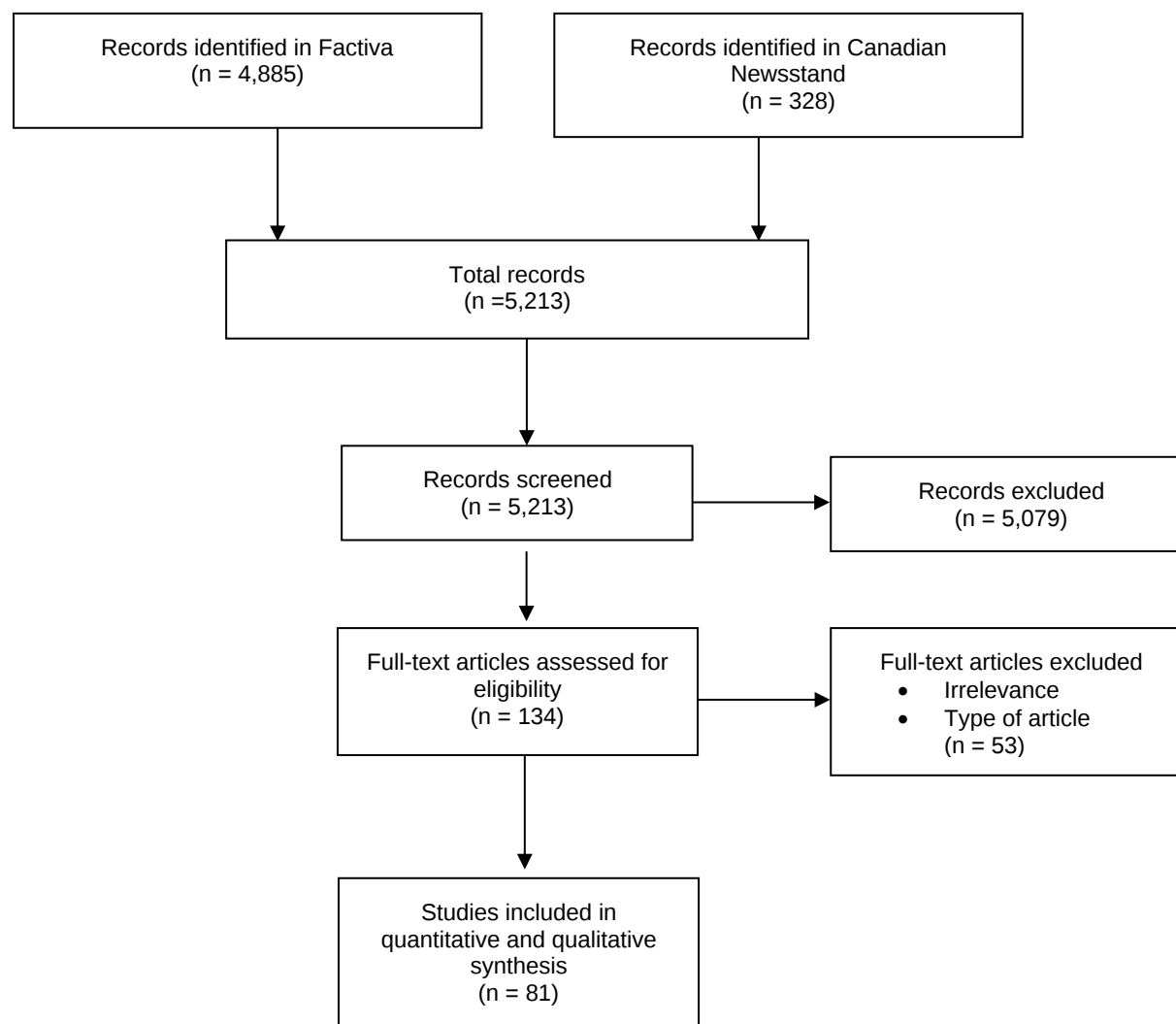
We analyzed the data using a discursive psychological approach (38). The focus of discursive psychology is to understand how issues, events, and experiences are constructed in everyday representations (38-41). Social texts such as news articles “do not just *describe* things; they *do* things. And being active they have social and political implications” (38 p.6).

To examine how social actors are positioned as responsible or not, we focused on subject positions. Subject positions are specific positions of agency and identity in relation to particular discourses (42,43). Subject positions may hold salient storylines, metaphors or imagery that become relevant within a particular context (42), and they may bear a particular set of rights and duties (44,45).

We developed a comprehensive preliminary qualitative coding framework based on our research objectives and the concept of responsibility. Coding was an iterative process that underwent several rounds of revision, and codes were developed both inductively and deductively. The identification of key ethical themes in the empirical and theoretical literature was used to build our initial codebook. In the preliminary round of coding, a list of codes deduced from the relevant literature was used to code and analyze a random sample of 20 articles. During this initial coding process, several more responsibility codes were created to capture how various aspects of responsibility were being constructed in the media articles. In the final stage of coding, the full sample of 81 articles were coded using the following responsibility codes: Individuals are personally responsible for developing ARLD; Individuals are not personally responsible for developing ARLD; People should not be faulted for developing ARLD; Alcohol use disorder is an illness; Alcohol use disorder is a mental illness; Alcohol use disorder is a genetic condition; People are victims of alcohol use disorder; Responsibility and the social determinants of health; Responsibility of society/culture; Responsibility of drinks/bar industry.

Once we identified who or what was positioned as the responsible agent(s) in each of the articles and for what they were being presented as being responsible, we used the method of discourse analysis, based in discursive psychology, to identify the subject positions and examine how representations of responsibility were worked-up in the discourse.

Figure 1: PRISMA Flow Diagram



Adapted from Moher and colleagues (48)

## ANALYSIS

We found three constructions of responsibility in our analysis. In the first section, we examine constructions of personal responsibility, which positions individuals as responsible for both developing and treating ARLD. In the second section, we present media articles that assign responsibility to biological factors, genetic predisposition, and disease. Finally, in the third section we analyze how political actors are positioned as responsible for creating a social environment that facilitates alcohol-related problems.

### Personal responsibility

Seventy-seven of the eighty-one media articles (95%) positioned individuals as either partially or entirely responsible for developing ARLD and for accessing treatment. Individuals are positioned as responsible for developing ARLD by consuming alcohol and failing to comply with doctors' orders. Individuals are described as responsible for treating their ARLD by maintaining abstinence, convincing doctors they can remain abstinent post-transplant and taking care of their donated liver.

### *Responsibility for Developing ARLD*

The first extract was selected for its portrayal of how individuals are positioned as personally responsible for developing ARLD by consuming alcohol. It tells the story of an individual on the waitlist for a donated organ, awaiting a transplant procedure: "Boozer at 10... New Liver Age 26" (Daily Star, January 10, 2012).

Matt Maden was regularly downing eight cans of lager in one session by the time he was 16. A year later he would routinely drink up to 16 pints before moving on to spirits after turning 18. By the age of 21 he was diagnosed with cirrhosis of the liver. Even after falling into a booze-induced coma for two weeks and having to learn to walk again, Matt remained in “total denial” about his addiction. Now he is living on borrowed time and spends his days waiting by the phone for news of a donor organ. He said: “How I behaved in the past was really, really selfish. I can’t imagine what I must have put my family through. It must have been heartbreaking”.

Maden’s personal responsibility for developing ARLD is constructed through the detailed description of the amount of alcohol that he “routinely” consumed leading up to his diagnosis. Potter comments on how quantification of descriptions can make something seem extreme or minimal, or construct something as good or bad (43). For example, the journalist describes Maden as drinking high volumes of alcohol “regularly” in one sitting. These descriptions present liver disease as a direct and self-inflicted consequence of Maden’s drinking, including after he experienced adverse health consequences. Maden is also positioned as accepting responsibility for his ARLD requiring transplantation. This positioning is accomplished by the journalist quoting Maden atoning for past behaviour by apologizing for the harm caused to his family. Using a direct quotation allows the journalist to use Maden’s active voice to describe personal responsibility and repentance: “How I behaved in the past was really, really selfish. I can’t imagine what I must have put my family through. It must have been heartbreaking.” Through this apology, Maden is positioned as taking responsibility for what is portrayed as a self-inflicted ailment.

The article describes Maden as someone with an alcohol addiction. In some instances, representations of addictions can position responsibility for ARLD as factors beyond an individual’s control, such as their genetic predisposition. While this notion of responsibility is not invoked in Maden’s case, later in this analysis we examine how alcohol addiction is sometimes represented as an illness beyond an individual’s control.

### ***Responsibility for the Gift of Life***

The next extract illustrates the subject positioning of the organ recipient as a gift recipient with certain responsibilities. The organ-as-gift is a well-entrenched metaphor in transplant discourses. Organs are considered a “gift” because donation is an act of altruism with no expected reciprocal obligation, as is the norm for most gifting processes. Recipients of this gift are positioned as responsible for being good stewards of their new liver and their bodies by remaining abstinent: “Livers for more alcoholics? Study says sickest patients shouldn’t have to wait until they’re sober six months” (*St. Louis Post-Dispatch*, November 10, 2011).

Preschool teacher Jane Sussman, 59, has been waiting for a liver for more than a year. Doctors aren’t sure what caused her liver condition, but she has never been a drinker. She doesn’t want the list to get longer by adding more alcoholics. “Who knows for sure if they’re not going to start drinking right way [sic]?” Sussman said from her temporary home in Pittsburgh near her transplant hospital. An organ is “the most amazing gift you’ll get in your life. If you don’t treat it right, it’s a wasted gift that could have gone to someone else, like myself.”

This description creates a dichotomy between patients with liver disease who are portrayed as deserving and those who are considered undeserving of treatment and resources. The journalist positions Sussman as not personally responsible for her illness, in contrast to those with ARLD: “[d]octors aren’t sure what caused her liver condition, but she has never been a drinker”. The quote “She doesn’t want the list to get longer by adding more alcoholics” works to position Sussman, a preschool teacher (a socially respected profession), as more deserving of a transplant than “alcoholics”, a stigmatized identity. The article affords her the moral authority to question the responsibility and intentions of ARLD patients: “Who knows for sure if they’re not going to start drinking right way? [sic]” This description constructs a stigmatized image of ARLD patients as individuals who may waste the “gift” of a resource that “could have gone to someone else, like myself”. There is a consequentialist assumption behind prioritising non-‘alcoholics’ as well: Sussman is positioned as more deserving of the scarce resource than someone with ARLD, because she did not ‘cause’ her liver disease nor is she likely to ‘waste’ the gift. People with ARLD are positioned as personally responsible for developing the ARLD, as well as likely to continue to consume alcohol post-transplant.

### ***Responsibility for ARLD Treatment***

The following extract positions patients as responsible for listening to their doctors and following their advice if they want to avoid emotional pain and their own death. There may be an additional expectation that patients will be adherent if they hold identities that suggest a duty toward others, such as the gendered identity of ‘mother’: “Mother facing liver disease tells of ‘constant pain’” (*Evening Express*, July 14, 2015).

And the mum-of-three is telling her story in the hope it will dissuade others from following in her footsteps. She said: “Doctors have told me these are my last days, I have no more than a couple of months to live. “I was warned and warned by doctors to stop drinking and I didn’t. There’s no higher price to pay than the one I’m paying now and that’s with my life”. Hazel says she wants other people to read her story, learn from her mistakes and be aware of what alcohol can do to you. [8 lines omitted] One of her daughters is due to give birth in December – but Hazel knows she will never meet her first grandchild. She said: “I won’t be here to meet them. My little girl is going to need her mum to help her through it too, but I’m not going to be around to do that for her. I would love to have held that baby in my arms, I would have spoilt it rotten like a granny should. I feel guilty about that every day.”

The positioning of Hazel as a mother is accomplished through repeated descriptions of her relationship to her three children, and to the future grandchild she laments that she will not meet. According to Hallowell, women often feel that they have a responsibility to their family to remain healthy, so that they can participate in “mothering work” (50, p.611). The article uses active-voicing (43) to portray Hazel’s maternal obligation: “My little girl is going to need her mum to help her through it.” By positioning Hazel as a regretful mother, the article portrays her as taking moral responsibility for the development of ARLD.

Hazel is portrayed as a citizen who has internalized the discourse of personal responsibility, positioning herself as personally responsible for the development of the disease. She is quoted as taking responsibility for not heeding the doctors’ warnings and continuing to consume alcohol despite the progression of the liver disease, she says: “I was warned and warned by doctors to stop drinking and I didn’t.”

Hazel’s imminent death is described using an extreme-case formulation (43), i.e., a semantically extreme example to legitimize claims. For example, drinking is described as directly leading to Hazel’s painful, imminent death: “There’s no higher price to pay than the one I’m paying now and that’s with my life.” This extreme-case formulation works to present Hazel’s experience as a cautionary tale of the risks associated with failing to take immediate and prudent responsibility for one’s alcohol consumptions and thereby one’s own health.

## Biological Factors

Ten of the articles we analyzed indicated that biological or genetic components may be at least partially responsible for the development and progression of ARLD. Framing the disease as related to biological factors challenges the extent to which patients could be held personally responsible. Indeed, a biological condition, which is supposedly beyond individual control, suggests that the afflicted individual is at least not primarily responsible. A possible genetic component that either causes an individual to have reduced control over their alcohol use or predisposes someone to develop liver disease (20,51) would reduce an individual’s ability to control their disease progression, thereby diminishing personal responsibility.

## Genetic Factors

The following two extracts discuss the Canadian court case of Deborah Selkirk, whose husband Mark died from ARLD after being denied a transplant, since he had not completed a six-month abstinence period. In the first article, the journalist quotes a national study on liver transplantation published in the *Canadian Journal of Gastroenterology* (6) to support the positioning of ARLD as a genetic disease:

“Surely patients in a just society should not be penalized for having a genetic predisposition to a potentially fatal disease,” the authors say, calling for the six-month rule to be revisited. (“Widow challenges transplant rules; Alcoholic husband denied liver operation” *The National Post*, November 2, 2015).

The news article is critical of the six-month rule; the current policy is presented as unjustifiable in light of the recent scientific evidence.

The opinion piece “The deathpanel policy; Regulations requiring alcoholics to be dry for six months before receiving a liver transplant represent a serious bureaucratic overreach” published in the *National Post* (November 3, 2015) problematizes causal attributions of personal responsibility for disease and access to healthcare resources.

Do car accident victims who were wearing seat belts get triaged in the emergency room before car accident victims who flouted the law? What if their injuries are equally serious? What if the seatbelt wearers weren’t as badly hurt? Does this not quickly become an exercise in passing moral judgment, rather than making medical decisions about saving lives? And what of the significant role genetic predisposition is said to play in alcoholic liver disease? Have we decided it’s necessary to punish individuals who have inherited this particular physical weakness, but not, say, those with a family history of diabetes, whose condition similarly depends on “lifestyle” choices?

The author uses an analogy of two car accident victims to describe resource allocation in a way that criticizes the six-month rule. This account also raises the possibility that ARLD may be the result of a “genetic predisposition”, a hereditary “physical weakness”. If substance use, ARLD, or both involve a genetic component then the responsibility for the disease lies within the

human genome, not within the 'person.' If this is the case, the author argues that requiring six months of abstinence is "an exercise in passing moral judgment" and not "a medical decision about saving lives."

### **ARLD as Illness**

The article "Fighting the demon; Last week it was revealed the North East has the highest rates of hospital admissions for liver disease in the country" directly renders alcohol addiction as an illness. This article from the UK chronicles one person's experience with alcohol use and his successful recovery from ARLD following a liver transplant (*The Newcastle Chronicle & Journal*, April 25, 2013).

To the people who believe Kirk is undeserving of a transplant as he brought his problems on himself, he says: "I didn't plan to be an alcoholic. You wouldn't plan that misery for yourself." He also views addiction as an illness that requires lifelong abstinence.

Narrative accounts have the benefit of being able to use documentary and or biographical material to portray the "moral identities" (43, p.172) of individuals. In this narrative, ARLD is constructed to be the result of an illness, not a moral inadequacy. Kirk is quoted saying, "I didn't plan to be an alcoholic. You wouldn't plan that misery for yourself." Kirk's statement works to construct the drinking behaviour as non-voluntary: alcohol consumption is not a 'choice' for which Kirk can be held personally responsible. This moral positioning is in contrast with Maden's and Hazel's narratives, where they both take a position of personal moral responsibility through apology. Kirk is described as being abstinent for over a year prior to the transplant operation, and abstinence and deservingness are presented in a contingent relationship. Kirk is positioned as deserving because he made a 'choice' to abstain from alcohol; in the context of liver transplantation and resource scarcity, this is akin to taking responsibility for one's own health.

### **Political actors**

Eight of the articles that we analyzed attributed responsibility to political and industry actors. This group encompasses people with political influence, such as politicians or social policy advocates, and institutional actors such as the alcohol industry. This section describes how several news media articles construct the issue of alcohol use and liver disease as the result of failed population-based policy initiatives aimed at reducing overall alcohol consumption and alcohol-related harms.

The following article was published in the UK's *Metro* newspaper: "Rising alcoholism leaves us facing 'liver disease crisis'" (April 29, 2013).

The number of alcoholics receiving liver transplants is also on the rise, with shadow public health minister Diane Abbott, whose parliamentary question saw the statistics released, saying England is in the midst of a "liver disease crisis." She called for prime minister David Cameron to revive plans for a minimum price per alcohol unit. "We need a comprehensive alcohol strategy," Ms Abbott said. "It should address licensing reforms, marketing, advertising, education, public awareness and a minimum unit price."

In placing responsibility on policy makers to resolve the "liver disease crisis" by making changes to "licensing reforms, marketing, advertising, education, public awareness and a minimum unit price", the author presents the issue as one that is the result of failed public policy rather than the result of failed individual morality. The crisis is understood to have political origins and political solutions; the Prime Minister is positioned as accountable for the current situation.

The article "Steep Societal Cost of Alcohol" written by physician Edward Xie (*The Toronto Star*, July 11, 2013) describes how the financial interests of governments and policy makers may be influencing the debate about whether to extend alcohol sales to convenience stores in Ontario, Canada.

Some politicians want to make this about choice. People do not choose to become addicted to alcohol, or develop permanent liver failure, or miss work, or become victims of a drunk driver. The paramedics, nurses, police officers and social workers I work with all understand these problems. Economists and researchers get it, too. Nevertheless, when it comes to policy-making, the real costs and the real suffering don't get much attention.

The category of physician – i.e., medical content expert – is worked up in the discourse through description of the various consequences of alcohol consumption Xie has witnessed in the hospital, including people awaiting liver transplant. Xie uses his medical experience to position people living with the consequences of alcohol use as victims rather than responsible agents: "[p]eople do not choose to become addicted to alcohol, or develop permanent liver failure." Similar to the genetic positioning described earlier, Xie argues that patients should not be held entirely morally responsible for their consumption; it is a behaviour that is influenced by societal conditions, including the calculated decisions of policy makers. Policy makers decide how and where alcohol is sold, and these decisions affect the lives of patients treated by healthcare professionals like Xie; the increase in the accessibility of alcohol will result in higher rates of alcohol-related morbidity and mortality. This description positions policy makers as responsible for the harms caused by alcohol, through developing policies that Xie and public health scholars understand to be harmful to individuals and populations.

## DISCUSSION

The majority of the articles in this study ascribe responsibility for ARLD to individuals living with ARLD. Individuals are positioned as responsible for developing their liver disease, treating their ARLD, and maintaining their transplant. These findings are consistent with results from media analyses of addiction discourses in Canada, Italy, Finland, and Poland that found increasing rates of individualization, where personal responsibility is ascribed to people living with addictions (14,30,31). Positioning people as personally responsible for their ARLD is a moralizing action that is aligned with ingrained social and cultural values in North America and the UK – which include neo-liberal values of productive citizenship, vulnerability, risk and self-control – values thought to be threatened by people who consume high volumes of alcohol or other substances (52). Direct quotations from people with ARLD in the selected articles demonstrate how these values can be internalized.

Eight of the articles that we analysed ascribed responsibility to policy makers or political actors. Population-based approaches to alcohol control include establishing restrictions on advertising, limiting bars' operating hours, setting strict controls on alcohol sales and distribution, and increasing taxation (53-55). The limited focus on macro-level factors is surprising given that policy-level approaches are among the most effective means for reducing alcohol-related problems in a society (56). Population-based approaches are not favoured by alcohol industries; instead, alcohol industries promote education programs that encourage individuals to self-regulate their alcohol use (57). These education programs appear to be unsuccessful at reducing consumption (58,59) and have been criticized for downloading the burden of responsibility for their own health onto individuals (60).

Another significant contribution of our analysis concerns the role of media in perpetuating stigmatizing language about marginalized populations, their ability to take responsibility for their (ill) health, and their claims to scarce health resources. For instance, it is well established that the language that some journalists use to describe people who use substances perpetuates stigma. Many of the media articles we analyzed include words such as "addict" and "abusers." This stigmatizing language also includes metaphors of hygiene often associated with substance use, such as being "clean" (i.e., abstinent). Such language is harmful; it is not based in science and it is disrespectful. Stigmatizing language may influence the thinking and behaviour of those who use such language by altering the perceived cause of the behaviour and the amount of control affected individuals are understood to have over their actions (61). Kelly and colleagues find that the use of terms such as 'addict' and 'abuser' "may evoke implicit punitive biases and decrease patients' own sense of hope and self-efficacy for change" (61, p.9). The perpetuation of stigmatizing language towards people who use substances may influence individuals' willingness to access support and treatment for substance use disorders (61,62).

To counter the intensification of stigma, we suggest that journalists and media sources follow recent guidelines (61) around language use and reporting when discussing issues related to substance use. These guidelines include using person-first language (e.g., "a person who uses alcohol", instead of labelling a persons as an "alcohol abuser"), and using medically appropriate language to reduce stigma and improve treatment seeking and adherence. However, while such a change in language is necessary it is not sufficient. For example, a recent study of the influence on journalists of the 2017 Associated Press' Stylebook – which recommended against using stigmatizing language to describe people who use substances – found limited evidence of a decrease in stigmatizing language across included publications (63).

The language the media uses to describe stigmatized health conditions and access to scarce resources has important implications for health equity. Media messaging may encourage social distance from stigmatized groups as well as the transmission of stigma messages within broader social networks (15). This compounded stigma can intensify existing health inequities (64). Furthermore, populations who are stigmatized in one domain (e.g., health) are likely to be stigmatized in other socially structured domains (e.g., race, gender, class). The influence of the media in shaping public support for social policies or programs that govern the behaviour of stigmatized populations cannot be overstated as compounded stigma can intensify existing health inequities (65).

## Limitations

Our study has its limitations. First, our sample of news media articles was intentionally restrictive; we did not include social media sources such as blogs, Twitter, and Facebook, where many people currently access news and other information related to health and illness. Second, we only included English-language articles. How responsibility for ARLD requiring liver transplant is constructed in news media in other languages may provide additional perspectives on this issue. Third, we did not compare similarities and differences in portrayals of responsibility across countries, within countries, or the incidence of different viewpoints over time. Addressing these limitations would be fruitful areas for future research.

## CONCLUSION

The aim of our paper was to investigate how the news media represents responsibility for ARLD requiring a liver transplant. Our analysis suggests that while publics from different countries tend to be exposed to one view of personal responsibility, evidence of alternative positions foregrounding biological, social and political factors suggest that responsibility for ARLD is a nuanced concept. Discourse analysis allowed us to identify several rhetorical strategies used in the articles that worked to construct responsibility for ARLD requiring liver transplantation. These strategies include narrative accounts, which have the ability to put the moral identities of individuals on display (43); the use of direct quotes and active voicing; and extreme case formulations that mobilize examples of harm done by consuming alcohol. Additionally, in this analysis we showed how the language that the media uses to describe people living with ARLD may perpetuate stigma. Our study complements existing media analyses surrounding the effects of stigma communication (65) and provides a foundation for future work to investigate how responsibility is presented in diverse media sources for other stigmatized health conditions, and the potential consequences for population health inequities.

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None to declare

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