Case management and patient navigation models for people living with or at risk of HIV

Questions

What case management and patient navigation models exist for people living with or at risk of HIV?

How do these models determine client care?

How has the effectiveness of these models been measured?

Key Take-Home Messages

- Common approaches in the models examined included a strengths-based approach to care to encourage clients to use their inner strengths to gain resiliency (1, 2) or a team-based approach which included various service providers to assist with client needs (3, 4). Interventions also used integrated (5) or holistic models (6) to address both clinical outcomes as well as social barriers to care.

- Many studies examined client care through population-focused interventions such as those among individuals recently released from prison or jail (7, 8), transgender individuals (9, 10), and individuals experiencing homelessness (11).

- Evidence shows mixed results in terms of effectiveness of case management (12), while patient navigation models generally have moderate to positive findings (13). Many studies show positive effects in terms of improving linkage to care (2, 14), retention in care (15, 16), and clinical outcomes such as decreases in viral load (4, 15).

Rapid Response: Evidence into Action

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Suggested Citation
Rapid Response Service. Case management and patient navigation models for people living with or at risk of HIV. Toronto, ON: The Ontario HIV Treatment Network; December 2020.

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The Issue and Why it's Important

A goal of HIV care is to maintain viral suppression through medication adherence (17). Due to difficulties in accessing medical care or adhering to treatment, many individuals living with HIV may not achieve or maintain viral suppression (18). A recent literature review found that case management interventions facilitate timely linkage to HIV care (19). In simple terms, case managers act as broker agents by referring clients to service providers (20). Intensive case management models include co-located services to address a wide variety of client needs (a team-based model) or empowerment strategies to build client skills and abilities (a strengths-based model) (20). Byun et al. (2019) examined descriptions of the qualifications for a case manager from nine U.S. states and made recommendations based on the needs of the Utah Health Department. Their recommended qualifications for a non-medical case manager included: 1) possess at least an associate's degree in health, human, or education services, and 2) have one or more years of case management experience with people living with HIV, and/or persons with a history of mental illness, homelessness, or chemical dependence (21).

Patient navigation services were initially created as a way to increase timely access to cancer care among marginalized populations, and its methodology has expanded to other chronic diseases such as HIV (22). Although there is no consensus on a common definition in the literature, patient navigation has been described as “...a model of care coordination that shares some characteristics with advocacy, health education, case management, and social work” (23). Patient navigators can consist of social workers, nurses, lay health workers, or peers (22). Patient navigation services are developed to meet the needs of the individual and may include activities such as assisting with appointment scheduling, transportation, appointment accompaniment, referrals, health education and counselling (13).

Interventions which examine case management and patient navigation models, or combinations thereof are explored in more detail in this review.

What We Found

State-level models of HIV care

Ryan White HIV/AIDS Program

In the U.S., outpatient HIV health care facilities receive funding from the Health Resources and Services Administration’s (HRSA) Ryan White HIV/AIDS Program (RWHAP) to provide medical care, essential support services and medications that help low-income, uninsured, and underserved people living with HIV remain in care and adhere to treatment (24). More than half of people living with

References


diagnosed HIV in the U.S. (i.e. more than half a million) receive services through the Ryan White HIV/AIDS Program each year (24). Viral suppression among Ryan White HIV/AIDS Program clients was at 85.9% in 2017, which was higher than the national average of 59.8% (24). Approximately 75% of Ryan White Program-funded facilities provide on-site case management, which provide assistance with food, housing, and transportation (25).

A 2018 longitudinal study examined the effectiveness of a medical clinical management service as part of the Ryan White HIV/AIDS Program in an infectious disease clinic in the midwestern U.S. (26). Health outcomes were compared between clients who received medical case management (which included services such as insurance assistance, transportation, housing, food services, adherence counseling, and linkage to care) versus clients who did not receive medical case management (26). Results demonstrated that clients receiving case management had significantly faster improvements in clinical outcomes, such as decreased viral load and increased CD4 cell count, than those in the comparator group. Authors concluded that these results suggest the importance of medical case management in improving health outcomes for people living with HIV (26).

The New York City Ryan White Part A Care Coordination Program (CCP) launched in 2009 (27) to address HIV/AIDS healthcare disparities (28). The four components of the Care Coordination Program included patient navigation, health promotion, treatment adherence, and benefits and services coordination. Specific intervention components included: 1) reaching out to initial cases and to those who miss an appointment; 2) case management such as coordinating access to social services and benefits assessments; 3) decision-making for cases by multidisciplinary care teams; 4) patient navigation which included appointment reminders, transportation services, and accompaniment to primary care visits; 5) adherence support for antiretroviral treatment; and 6) a planned health promotion curriculum (27). A 2017 study found that the program increases short-term viral load suppression after 12 months of follow-up (27). This was followed by a 2019 study which examined the long-term effectiveness of the program among participants enrolled from 2009–2013 (18). The 2019 study compared durable viral load suppression at 13–36 months of follow-up between matched enrolled and non-enrolled participants (18). Authors found that the intervention had a positive effect on durable viral load suppression among participants who were unsuppressed in the year before enrollment, but not among those who were newly diagnosed or had consistent viral suppression in the year prior to enrollment (18). Based on these findings, study authors suggest recruiting individuals to the program who do not have evidence of recent viral load suppression (18).
**The Max Clinic**

The Max Clinic model was developed after researchers evaluated two strategies in the State of Washington to reengage patients in HIV care that proved to be only modestly effective (29) or ineffective (30). The researchers reasoned that “...no single intervention was likely to have a meaningful impact, and that a more effective intervention would include an array of interventions and a fundamentally different model of care delivery” (31). This led to the development of the Max Clinic model in 2015 which included high-intensity support, low threshold access, and incentives for retention in care and viral suppression (31). Aspects of the high-intensity approach consisted of intensive patient support and outreach from nonmedical and medical case managers who served as a single point of contact for coordinated care (31). The clinic offered a low threshold to care as case managers could be accessed five days per week on a walk-in basis, contacted through a direct phone line, and offered the option to communicate via text message (31). Other coordinated services included adherence support, mental health case managers, supportive housing programs, and jail release planners (31). A 2020 qualitative study on patient’s perceptions of the Max Clinic found that engagement was strongly influenced by their ability to access care on a walk-in basis, their relationships with clinic staff, and the fact that coordinated social services were able to meet their needs in a timely manner (32).

**Data to Care**

Data to Care (D2C) is a public health strategy in the U.S. with the primary goal of increasing the number of persons with diagnosed HIV who are engaged in medical care and to increase the number of HIV-diagnosed persons who are virally suppressed (33). Data to Care initiatives allow for opportunities to develop existing collaborations as it requires collaboration between the health department, medical providers, and essential support services (33). Some Data to Care activities include using HIV surveillance data routinely collected by state and local health departments and other data sources. By doing this, individuals with different needs can be identified, including supporting those with linkage, reengagement, or viral suppression challenges, and pregnant women or mothers who might need HIV service coordination (33).

Various studies have examined Data to Care interventions:

- A 2020 study examined a program called Louisiana Links, which incorporated a patient navigation system (34). The program used secondary data sources to identify individuals not in care and linked them to staff who helped them navigate health services and address barriers such as access to transportation and insurance (34). Results found that over the course of the study, those who were newly
diagnosed were 56% more likely to link to care and those not in care were 17% more likely to reengage in care than those in the comparison group (34).

- A 2020 study in San Francisco examined HIV care continuum outcomes using Data to Care referral strategies to identify and relink individuals to care (15). This intervention included providing those reengaged in care with short-term case management services (up to 90 days) by a designated navigator (15). Navigators assisted by providing appointment reminders, clinic accompaniments, and modified antiretroviral treatment (15). Results showed improvements in retention and viral suppression, as 70% of those who became virally suppressed during the intervention, maintained suppression at the follow-up period (15).

**Tiered model of care**

Based on a review of case management practices across nine U.S. states, Byun et al. (2019) adopted a tiered model for use in Utah and combined it with scoring where each tier represented a range of acuity scores (the higher the score, the greater the need for social services) (21). Each tier was linked to an appropriate level of case management services (21). The authors recommended that the ideal tiered model be composed of three tiers: Maintenance Outreach Support Services (for low acuity patients: 8–15 points), Brief-Contact Management (for middle acuity patients: 16–23 points), and Medical/Non-Medical Management (for high acuity patients: more than 23 points) (21). See Table 1 on page 6 for the tiered model recommended by Byun et al. for HIV case management in Utah (21).

**Community level models of care**

In British Columbia, AIDS Vancouver provides the Health Promotion Case Management (HPCM) program which includes short-term, outreach-based case management services for individuals at high risk for HIV infection (1). Case managers work with clients for one to five months to identify their clients’ strengths, values, and behaviours (1). Case managers work to decrease their clients' risks for HIV by focusing on their strengths and resiliency to develop their personal skills and self-efficacy (1, 35). Case managers also address structural level barriers by assisting with income, housing, immigration, and legal issues (1). The program has an existing partnership between AIDS Vancouver and Vancouver Coastal Health, through which clients can be referred to for additional clinical services (1). The program aims to transition clients into a network of other services and medical providers who can assist clients with maintaining their health and reducing their risk for HIV (1). When transitioning out of
<table>
<thead>
<tr>
<th>Patient tier</th>
<th>Maintenance outreach</th>
<th>Support services brief-contact management</th>
<th>Medical/non-medical management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of contact</td>
<td>Points from acuity scale</td>
<td>Tier definition</td>
<td>Points from acuity scale</td>
</tr>
<tr>
<td>1 time per year</td>
<td>8-15 points</td>
<td>Targets people living with HIV who are successful in self-management; is intended to monitor the sufficiency of self-management and to provide additional services, when appropriate, to prevent lapses in care</td>
<td>16-23 points</td>
</tr>
<tr>
<td>Contact with patient at a minimum of 2 times per year</td>
<td>24 or more points</td>
<td>An empowerment case management model intended to assist persons living with HIV/AIDS to achieve independence in decision-making and accessing services for their health related and/or psychosocial needs</td>
<td>4 times a year</td>
</tr>
<tr>
<td>Contact with patient who has 32 or more points</td>
<td>24 or more points</td>
<td>A proactive case management model intended to serve persons living with HIV/AIDS with multiple complex medical and/or adherence-related issues, including evaluation of their sociospatial needs and/or psychosocial needs</td>
<td>Should be every 30-60 days until acuity scale drops below 32 points</td>
</tr>
</tbody>
</table>
care, clients are followed for an additional three to six months to ensure they are maintaining their positive health behaviours, and are able to return to the program at any time (1).

A 2017 qualitative study examined a new role in Wisconsin's AIDS/HIV program called the Linkage to Care (LTC) Specialist (6). The specialist provided short-term intensive case management and navigation services over a nine-month period for individuals who were at high risk for falling out of care (6). Specialists provided individualized services based on their clients' needs and took a holistic approach to address medical issues and social needs such as barriers to care, housing, and financial assistance (6). The program aimed to provide participants with the skills and knowledge they needed to maintain engagement in care after leaving the program (6). Results found that the specialists filled an important gap in social support, particularly among clients who had been incarcerated, and many clients were able to establish independence and self-efficacy upon leaving the program (6). Similarly, another 2017 study examined the role of a Linkage to Care Specialist (LTC-S) at a Los Angeles LGBT centre (2). Using a strengths-based approach, the specialist assisted clients with navigating negative emotions related to their HIV diagnosis and redirecting these feelings towards health seeking behaviours (2). This single-arm study was found to be effective as 94.1% of participants were linked to care within three months of their diagnosis (2).

A 2018 study in a St. Louis clinic examined a team-based approach called the Barrier Elimination and Care Navigation (BEACON) Project, implemented over a five-year period (2011–2015) (4). Each participant had access to intensive case management, a community HIV nurse, and a peer navigator (4). Emergency stabilization funding was included with intensive case management services which aimed to reduce barriers for HIV care engagement. This funding was used to pay for: rent and security deposits, addiction treatment, identification paperwork, and transportation services (4). Six months after the intervention, there was a significant increase in the number of individuals who had undetectable HIV viral loads, higher median CD4 counts, and improved general health (4).

A 2018 study examined a peer navigation and education intervention in comparison to standard care at three urban health clinics in Florida, New York, and Puerto Rico (16). The role of the peer navigator covered four main domains: 1) providing information related to HIV treatment and healthy living; 2) reducing barriers to care through knowledge of available services, appointment reminders, and accompanying appointments; 3) sharing personal experiences and actively listening to patients as a way to provide emotional support; and 4) connecting patients to social networks to assist them with maintaining care engagement (16). The intervention also included seven one-on-one education sessions on topics related to HIV care and treatment (16). Case managers also worked with patients to make referrals and assisted with applications for benefits and
other services such as housing. Results found that the intervention improved retention in care but there was no significant difference in viral suppression levels between groups after one year (16).

A 2019 study examined the Open Arms Healthcare Centre in Mississippi which implemented an integrated HIV care model aimed to improve HIV care continuum outcomes (5). The model included five main elements: 1) case management; 2) HIV health care; 3) behavioral health care; 4) adherence counseling; and 5) social support services such as transportation, housing, and legal assistance (5). Case managers assessed the psychosocial and medical needs of patients and worked with patient navigators to refer them to internal and external health care services including adherence counseling, transportation, housing, and mental health services within 24 hours (5). Based on an evaluation of patient data from 2015-2017, the authors found that antiretroviral adherence increased from 82.8% to 95.6%, and the viral load suppression rate increased from 59% to 81% within the three-year period (5). The study recommended a comprehensive approach to HIV care and access to social support services (5).

A 2019 study examined a program called the Kaiser Permanente HIV Test and Treat Initiative (KP Test and Treat) which included community engagement approaches implemented across seven U.S. sites through case management and patient navigation (36). Trained peers or community members acted as case managers or patient navigators who provided personalized approaches to assist clients with meeting their needs through one-on-one sessions (36). Some variations were found in services across the sites depending on the population being served (36). For example, women-focused programs also provided linkage to services for violence and trauma (36). Results found that in comparison to standard care, the program did not have a significantly greater affect on participants’ HIV care utilization, although stronger intervention effects were found among those who had lower baseline levels of HIV care engagement (36).

A Medicaid managed care plan, called MetroPlus Health Plan, was examined in a 2019 cohort study to determine the program’s effects on viral load suppression among enrolled participants in New York City (17). The program consisted of a street outreach intervention where trained peers contacted those not engaged in care, described as those who did not have a viral load test or primary care visit in the past nine months and/or did not have an antiretroviral subscription refill in the last six months (17). The program also included a peer care connection intervention for individuals engaged in care but had an unsuppressed viral load at their last test (17). This intervention involved care coordinators, peer educators, and peer counselors who assisted participants with activities such as psychosocial assessments, educational workshops, and adherence counseling (17). In the first two years of the program, 44% of participants contacted were virally suppressed and had higher odds of viral suppression...
compared to those who were not contacted (odds ratio OR=1.55) (17). Study authors concluded that individuals can achieve suppression through intensified outreach, care coordination, and peer support (17).

Population specific case management and navigation models

Individuals released from prison/jail

A 2020 systematic review of studies in the U.S. examined factors that can assist with linking individuals released from prison to hepatitis C or HIV care (7). The review found that confronting social determinants of health such as housing, income, food insecurity, and employment upon release was significant for linkage to HIV services (7). The authors found that case management could assist with providing inmates with community re-integration and access to health insurance (7). The study concluded that combining transportation assistance, case management, and discharge planning services together would offer released inmates the greatest opportunity for successful linkage to care (7).

Another 2020 systematic review examined interventions aimed at enhancing HIV care continuum outcomes among individuals released from prison or jail (8). Three identified interventions which utilized patient navigation services found improvements in HIV care outcomes (14, 37, 38). These and other interventions included:

- The LINK LA (Linking Inmates to Care in Los Angeles) randomized clinical trial examined the effects of a peer navigation model in comparison to standard care among individuals living with HIV being released from Los Angeles County Jail (37). The intervention consisted of peer navigators who were Black or Latino and had common experiences with incarcerated individuals (37). Peer navigators provided 12 counseling sessions over 24 weeks on topics such as goal setting and barriers to care as well as accompanying participants to HIV care visits (37). After 12 months, the proportion of virally suppressed individuals in the treatment arm did not change (49%); however, suppression in the control arm dropped from 52% to 30%, indicating a statistically significant difference between arms (P=0.02) (37).

- The SF Navigator Project is a randomized controlled trial which compared a navigation enhanced case management intervention to standard care among individuals living with HIV being released from San Francisco County Jail (38). Those in the intervention received 90 days of case management in addition to patient navigation services such as discharge planning as well as coaching and mentoring.


support (38). Results found that those in the treatment arm had greater odds of being linked to (OR=2.15) and retained in (OR=1.95) care than those in the control arm (38).

• The WI Linkage to Care project in Wisconsin examined linkage to care outcomes among individuals released from prison who received patient navigation versus those who did not (14). Patient navigation services included a time-limited, high-contact model with supports such as access to appointments, treatment adherences, housing, emotional wellbeing, and health education (14). Results found that 84% of those who participated in the patient navigation program were linked to care as opposed to 60% of those who did not (14). These findings suggested that intensive patient navigation is beneficial for those transitioning to HIV care in the community upon release from prison (14).

• A strengths-based case management intervention named “Sustained, Unbroken Connection to Care, Entry Services, and Suppression” (SUCCESS) provided for those living with HIV in an Atlanta jail (39). A feasibility study examined the intervention which consisted of six face-to-face strengths-based case management sessions which began in jail and continued upon release (39). Case managers used texting services to send appointment reminders and improve the participants’ connection to care (39). Results found that 52.3% of those in the intervention group were retained in care (defined as having at least two lab tests at 3-month intervals), versus 40% in the comparison group, suggesting a trend towards increased retention among those in the intervention group (39).

• A 2019 study examined an intervention in Louisiana that assessed the use of adding a case management video conference supplement to usual release services offered for Louisiana inmates nearing release from jail (40). The supplement was developed to allow case managers to create a plan for HIV care and to build a relationship with their clients, but the intervention group was not found to have a statistically significant difference in linkage to care when compared to the standard treatment group (40).

• A federally funded project (under part F of Ryan White HIV/AIDS Program) called EnhanceLink took place at ten sites in the U.S. which implemented diverse linkage to care services for individuals in prison and upon their release (41). At one of these sites, individuals who were linked by their jail-based case manager to a community-based case manager upon their release were nine times (OR=9.39) more likely to still be in care 12 months after their release than those who were not, suggesting the importance of continuous coordinated case management (41).
• A 2018 randomized controlled trial called Project Bridge in Baltimore, Maryland compared an intensive team-based case-management intervention to standard care among individuals on parole or probation living with HIV (3). Case managers worked with those in the intervention arm to develop unique service plans related to medications, housing, substance use treatment, mental health, income, and legal obligations (3). Other assistance provided by case managers included accompanying appointments, negotiating healthcare visits, and teaching participants about social service resources (3). Initial results at three months post randomization found no significant differences in time to HIV treatment or initiation of a medication regimen across treatment groups (3).

Transgender individuals

The literature also explores care management interventions for transgender individuals which includes:

• The Brandy Martell Project and the TransAcess project, both of which took place in the San Francisco Bay Area to increase linkage and engagement in care among trans women of colour (9). These projects incorporated trans women of colour to serve as patient navigators to assist participants by accompanying them to appointments and blood draws as well as providing benefits counselling and service referrals (9). Patient navigators served as a component of the projects which also included drop-in medical services, a legal clinic in the Brandy Martell Project, and behavioural health services in the TransAccess project (9). Results found significantly positive associations between peer health navigation aspects of the program and HIV care outcomes (9).

• The Alexis Project is an intervention combining peer health navigation and contingency management designed to assist trans women of colour in California progress along the HIV care continuum (10). The project included trans women of colour living with HIV as peer health navigators who assisted participants with developing a treatment plan to link to care and to access any additional services such as dental care, mental health counseling, and legal services (10). Results found that 85% of those enrolled were successfully linked to care, although the authors note they could not establish the extent to which the results were attributed to the contingency management or the peer health navigation aspects of the program (10).

Individuals experiencing homelessness

• A 2020 study examined a patient navigation intervention among unstably housed individuals living with HIV across nine sites in the U.S. from 2013–2017 (11). Navigators included peer and non-peer staff and provided intensive individual and system coordination to assist clients with linkage and retention to care as well as with their housing needs (11). A total of 43 activities across six domains shaped the intervention; these domains included: 1) health care activities such as appointment accompaniment; 2) mental health or substance use treatment support; 3) housing related supports; 4) social service or transportation assistance; 5) educational and emotional support; and 6) employment and other practical supports such as those related to obtaining food, clothing, and cell phones (11). Results found that the intervention had a significant effect on retention in care after 12 months among clients who participated in a high number of activities, but did not have an effect on viral suppression or stable housing (11). The authors noted that although navigation programs alone may not be enough to attain viral suppression, they do assist with addressing immediate barriers to care for those recently diagnosed with HIV (11).
Effectiveness of case management and patient navigation interventions

A 2016 publication examined the Antiretroviral Treatment and Access Study (ARTAS-I) which consisted of a multi-site randomized controlled trial in the U.S. that compared strengths-based case management sessions (up to five interactions with a case manager over a 90-day period) to a passive referral service for individuals recently diagnosed with HIV (19). The strengths-based model consisted of sessions facilitated by social workers to assist clients to use their inner abilities and assets to link to care (19, 42). Results found that within six months, significantly more individuals in the intervention arm saw an HIV clinician than those in the control arm (78% vs 60%) (42). A follow-up study (ARTAS-II) examined the effects of the case management intervention across 10 health department and community organizations and results demonstrated that it was an effective model in linking recently diagnosed individuals to care (19, 43).

In a 2018 review of HIV patient navigation literature, the Canadian AIDS Treatment Information Exchange (CATIE) found that some of the evidence was mixed, but the majority of studies found positive findings (13). Furthermore, the differences in the components of health navigation programs can make it difficult to determine what is facilitating improvements (13). Based on their review, CATIE reported 11 factors that can influence the success of a patient navigation program, which includes:

- Client characteristics: addressing client needs such as language and geographic barriers, and including culturally appropriate services
- Navigator recruitment and training: inspiring the growth of navigators, training for complex cases, and ensuring collaboration among navigators
- Time and resources: procuring human, financial, physical, and technological resources
- Community services: providing adequate resources in the community for referral
- Client uptake: using diverse recruitment strategies, addressing potential stigma, ensuring client buy-in (13).

A 2018 systematic review examined associations between HIV care continuum outcomes and patient navigation in the U.S. and found patient navigation to be positively associated with linkage to and retention in care (23). Patient navigation assisted those living with HIV to navigate complex medical systems and prevent them from falling out of care (23). Another 2018 systematic review examined patient navigation programs for individuals with chronic diseases in comparison to usual care (22). Seven studies related to HIV patient navigation were examined, six of which took place in the U.S. (22). Two of these studies showed significant differences between treatment groups in the primary outcomes examined which included attendance at an HIV clinic (42) and attending dental care (44). Due to high levels of heterogeneity across studies, the systematic review authors could not make a conclusive statement on the value of patient navigation programs (22).

A 2018 systematic review examined the effectiveness of organization of care (including case management, outreach programs, etc.) interventions among individuals living with HIV on various health outcomes such as medical, immunological, and psychosocial (12). Ten studies in this review described case management interventions in North America, and authors found that in-person case management and outreach interventions were associated with advances in immunological outcomes, economic outcomes, and healthcare use (12). Study authors concluded that further randomized controlled trials should be conducted to clearly identify the impact of case management on HIV associated outcomes (12).

A 2019 study examined the North Carolina Medical Monitoring Project and used 2009–2013 data from 910 individuals engaged in HIV care and found that depression prevalence was higher among those reporting case management (24.9%) than among other patients (17.6%) (45). Additionally, receipt of case management was not associated with antiretroviral adherence (45). The study found that more effective treatment
for depression was necessary even among those receiving case management services (45). The authors concluded that addressing psychological wellbeing, monitoring of antiretroviral adherence, and providing effective case management services are all necessary for HIV prevention and optimal clinical outcomes (45).

Factors That May Impact Local Applicability

Due to the numerous variations in case management and patient navigation models and interventions examined, it is important to note that any intervention would need to be adapted to meet the needs of local populations. A majority of the studies examined take place in the U.S. and therefore may not be entirely applicable to the local setting in Ontario.

What We Did

We searched Medline (including Epub Ahead of Print, In-Process & Other Non-Indexed Citations) using a combination of HIV in titles or abstracts AND (MeSH terms [Case Management or Patient Navigation] or terms [case management or navigation or patient navigation or service coordination or social service* or care coordination of coordination service*] in titles or abstracts). Searches were conducted on November 10, 2020 and results limited to English articles published from 2015 to present. Reference lists of identified articles were also searched. The searches yielded 593 references from which 45 were included.