Chapter 5
Supporting Complex Dynamic Health Journeys Using Conversation to Avert Hospital Readmissions from the Community: An Ecological Perspective Incorporating Interoception

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5.1 Background

The 80/20 or Pareto rule [1] applies to the health and disease distribution and the need for healthcare across communities: 20% of the population incurs 80% of all healthcare costs, particularly through hospital admissions and readmissions [2]. Rising costs of emergency department (ED) visits and avoidable hospitalizations in an aging population with multimorbidity and frailty have increased in parallel with

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family and community network disruption. Increasing health inequalities related to housing, welfare, and environmental challenges all compound the burden of ill-health on the healthcare system.

5.1.1 The Changing Role of Hospitals and the Health and Welfare System

Societies around the world are confronted with a rising burden of ill-health arising from the increase in preventable conditions like obesity as well as the increase in conditions associated with aging and frailty.

Not only does the healthcare system bear the brunt of acute, chronic, and acute-on-chronic medically recognized systemic conditions, but it also encounters the effects of the nonmedical *social determinants* of health, which extend into the purview of other jurisdictions including welfare, housing, transport, and justice.

Historically, the hospital was a place of support and healing. Hospitals have been described in very early texts as

> . . . houses for dispensing charity and medicine. All the poor and destitute in the country, orphans, widowers, and childless men, maimed people and cripples, and all who are diseased, go to those houses, and are provided with every kind of help, and doctors examine their diseases. They get the food and medicines which their cases require, and are made to feel at ease; and when they are better, they go away of themselves.
>
> A record of Buddhistic kingdoms; being an account by the Chinese monk Fâ-Hien of his travels in India and Ceylon, A.D. 399-414, in search of the Buddhist books of discipline
>
> J. Legge [3]

The modern hospital emergency department (ED) is a cross between a refuge for disadvantaged, "MASH" for the traumatized, and a gateway to "modern technology palace" for biomedical diseases.

> The appeal of the modern ED is undeniable - it is in some ways all things to all people. To the uninsured, it is a refuge. To the community physician, it is a valuable practice asset. To the patient, it is convenient, one-stop shopping. To the hospital itself, it is an escape valve for strained inpatient capacity. The demands being placed on emergency care, however, are overwhelming the system, and the result is a growing national crisis.
>
> The Evolving Role of Hospital-Based Emergency Care [4]

5.1.2 ED: At the Fuzzy Boundary Between "Medical Emergency" and "the Need for Social Support"

Hence the problem in preventable hospitalizations and emergency department utilizations is related to the complex systems in which they operate and the fuzzy rationale for their existence. Who should legitimately attend emergency departments and be admitted on an *emergency basis* to a hospital bed and who should be

redirected to *social support-oriented healthcare networks* to avoid the need for crisis care in an anticipatory manner?

Currently the modern ED is struggling to cope with complex and ill-defined demands arising from:

- The social determinants of health
- The lack of health system responsiveness
- True medical emergencies

5.1.3 The Role of Primary Care

Has primary care organized itself to accommodate the deprived, the disadvantaged, and the diseased in a friendly nonjudgmental manner? Arguably a person-centered approach can support people to access timely care in primary care without reaching some personal crisis point that lead them to seek supportive care in emergency services.

There have been alternatives to ED delivered "primary care" in the communities in Ireland and Australia; these models have fluctuated and lack the historical legacy of the ED. Primary care "urgent care services" do not provide direct access to the reassurance of hospital-based technology and wider resources. Individuals with opioid problems or with alcohol intoxication are actively discouraged from attending primary care services (Fig. 5.1).

Fig. 5.1 The emergency department—all things to all people. On one level, the ED dichotomizes people along the survival continuum into "life-threatening disease" and "minor illness." EDs also act as a "guiding source" to community care, temporary inpatient care, and/or organ-specific disease care. On another level, the ED is used to legitimize personal concern and act as a haven to address "psychosocial crises"

5.2 Health Journeys, Resilience, Interoception, and Anticipatory Systems

Individual life histories progress with episodic and/or cumulative loss of resilience causing an increased inability of an individual to respond to stressors—be they physical, psychosocial, and/or environmental—ultimately resulting in death. *Resilience* can be understood as the "capacity to bounce back" from stressors [5]. The inability to respond to stressors—internal or external—leads to greater tendencies toward unstable health states characterized by:

- More diagnosable diseases
- Greater severity of diseases
- Physical, social, and emotional dysfunction
- Disability

5.2.1 The Journey of Vulnerable People

The journeys of vulnerable individuals frequently include failures to detect triggers for instability that, if addressed in time, might avert avoidable emergency hospital utilization [5]. Emerging evidence indicates that unstable journeys with deteriorations over (2–3 days) occur usually in the home. Signposts of increasing instability include:

- Changes in illness experience
- Increase in pain
- Deterioration in mental state
- Deterioration in coping
- The emergence of "high-risk symptoms"
- Medication issues
- Carer stress and/or loss of carer
- Withdrawal of social support (perceived or real)
- Home challenges

Contact with health service providers may not flag the impending crisis or evoke adequate responses to ameliorate the situation or tipping point.

5.2.2 Anticipating Tipping Points in the Journeys of Vulnerable People

Anticipation of such tipping points, early warnings, and transitions in community journeys is considered the "holy grail" of prevention.

> An anticipatory system is a natural system that contains an internal predictive model of itself and of its environment, which allows it to change state at an instant in accord with the model's predictions pertaining to a later instant.
>
> Rosen [6]

There is much activity in this area. Human healthcare systems are increasingly learning from natural systems and seek to develop anticipatory systems to both improve individuals' and communities' health outcomes and manage health services more effectively.

Early warning systems to identify health deterioration are gaining scientific rigor and currency in healthcare, particularly in critical and frailty care [7, 8]. There are very few publications related to critical transitions and tipping points in emergency hospital utilization.

Biomarkers, biometrics, and patient-reported outcome measures increasingly can predict death, dependency, and disability [9]. Nevertheless, markers and metrics are not necessarily person-centered and orientated to personal health experiences and quality of daily life. Solutions abound with smartphones and sensors with self-monitoring or passive monitoring, and much work is needed to make these useful [10].

But very vulnerable individuals who are most at risk of hospitalization may have triggers which are not related to specific disease process or psychosocial and environmental crises. It is very difficult for standard "objective" population-based approaches to ascertain the meaning of a situation or conversely the situatedness of meaning of a potential health crisis [11, 12].

5.3 Conversations Provide Insights

Humans appear to have—at a deep intuitive level—evolved "the capacity to *know* their physiology and its trajectory" that otherwise is difficult to categorize—a phenomenon known as interoception [13]. Our human capacity for interoception is reflected in our "self-rated health perceptions." *Self-rated health* appears to account for physiology, meaning and situatedness, and has predictive power related to predicting mortality, hospital admission, and service utilization [14].

Regular conversations may tap into interoception of personal health states (self-rated health) but also provide information about the meaning and chronology of the experiences so that potential crises might be averted.

Conversations and narrative-based support over time help people make sense of their interoception in the context of their journey, as evidenced by the comments of this patient:

> You are a wonderful sounding board for how sick I really am. I can tell you my symptoms without necessarily knowing how sick I am and you can put in in perspective of whether I should be seeking further help and with whom. When I'm in a lot of pain or having breathing difficulties, I'm so focused on coping with that that I don't always have the foresight to work out what my next move should be - this is something that Monash Watch are really good at. Mick Dolan (pseudonym) in conversation with Sue W (Care Guide) in the MonashWatch service.

Potentially avoidable hospital (PAH) emergency attendances/admissions occur as a result of complex adaptive system (CAS) interactions in personal journeys influenced by:

- Internal biology, disease
- Personal sensemaking, strongly linked to feeling ill/pain or anxiety
- External healthcare, social, and environment

Self-care support in PAH improvement requires increasing, but varying, levels of clinical, personal, appraisal, informational, and practical support as illness becomes unstable.

5.4 Implementing the Patient Journey Record System (PaJR) in Ireland and Australia

The Patient Journey Record System (PaJR) applies a complex adaptive person-centered approach to understand and manage potentially avoidable hospitalizations (PAH). Telecare guides (TCG) regularly converse with "at risk" individuals to track their concerns and self-perceived health.

PaJR was initially piloted in a rural Irish cohort who were deemed to have had 1 PAH in the last year.

The framework is now being trialled by MonashWatch (MW), an Australian deprived inner-city cohort, who are predicted to have 3 PAH/year using hospital analytics following an index event.

5.4.1 Irish and Australian General Practice Systems

Both Australia and Ireland have a "British" model of general practice with some differences.

The Irish system is a blended capitation and private model with a well-organized out-of-hours primary care system with GPs contracted to provide 24/7 care for their capitated patients. This has led to a centralized "safety net" system with nurse triage and local GP and nursing teams working with community GPs providing consultations and home visits for many with at risk of potentially avoidable hospitalizations.

The Australian system has a fee-for-service model with ad hoc after-hours arrangements, including home doctor visiting which in many cases can be competitive with clinic-based services that are open for a wide variety of hours.

There is no centralized round-the-clock organization in Australia, while in Ireland a database of OOH utilization is available for quality improvement and research. The Irish system provides a traditional model for GP patients still

predominantly retaining a non-corporate model, particularly for acute minor illness and subacute potentially serious illness with OOH "homes" for crises.

Emergency departments tend to operate on similar principles in both countries. The Irish system had an adjusted health expenditure (%GDP) of 14.2% compared with Australia 10.2%. Per 1000 population Ireland versus Australian reports: 17.5 vs 11.5 nurses, 4.2 vs 3.5 physicians, 3.5 vs 3.8 acute beds, and 157.2 vs 172.9 hip replacements [15].

5.4.2 *Irish Primary Care Cohort (IPCC)*

The PaJR Ireland IPCC pilot study was conducted in 2009–2013 [16, 17] aimed to reduced avoidable hospital attendances in 198 patients (+90 controls) in three settings (Fig. 5.2).

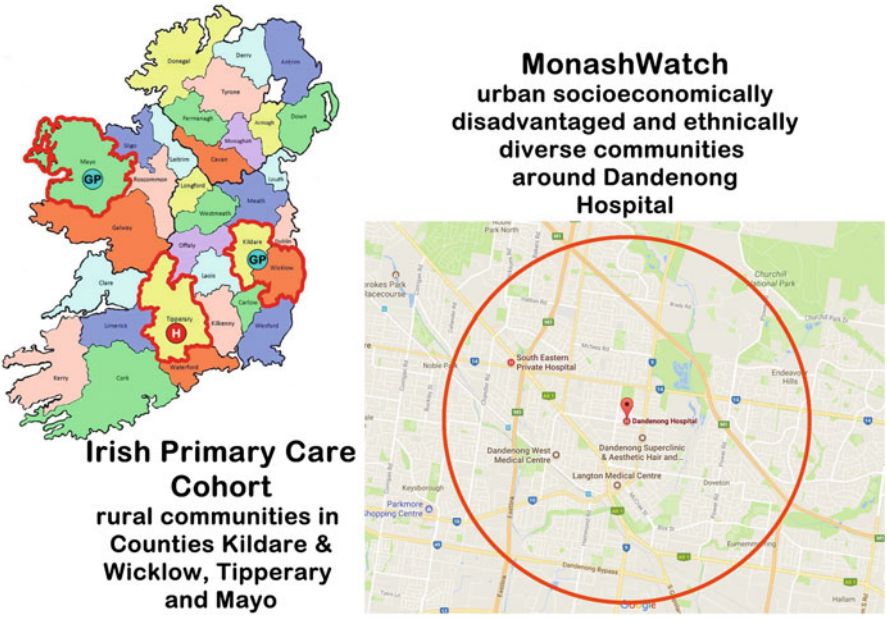

Fig. 5.2 Comparison of geographic and services characteristics between the trial sites. Irish cohort: GP out-of-hours service (County Kildare and western part of County Wicklow), GP practices around Castlebar (County Mayo), and patients discharged from Nenagh Hospital (County Tipperary). MonashWatch cohort: patients who can be visited within 10 min drive from Dandenong Hospital

Recruitment criteria were:

- Having been admitted to a ward with at least one overnight stay
- Having one serious chronic disease—congestive health failure, chronic lung disease, diabetes, and other serious conditions such as cancer (in remission) and inflammatory bowel disease
- Likely to be socially isolated

Patients and controls were recruited consecutively: on hospital discharge—Co. Kildare & western Co. Wicklow, and recruited through GP practices based in Co. Mayo. The ratio of intervention:control was 2:1.

5.4.3 MonashWatch (MW)

MonashWatch is a scalable small locally based team approach beyond traditional silos of services that aims to be a holistic, proactive, intensive, and timely approach to avert potentially preventable admissions.

Based on DHHS Chronic Care Links (HLCC) (Box) algorithms, the eligible Monash Health cohort was identified. Predictive analytics based on hospital datasets identified a cohort with predicted 3+ overnight stays and/or hospital ward admissions. Patients predicted to have 3 PAH in the next 12 months were entered into the MW program after an index event, either admission or ED attendance.

The MW program is an outreach service of Monash Health, the largest public health service in Melbourne, Australia, providing services to almost a quarter of metropolitan Melbourne's population of 4.4 million people.

Hospitals including Monash Medical Centre Clayton, Moorabbin Hospital, Dandenong Hospital, Casey Hospital, Kingston Centre and the Cranbourne Centre, and Community Services provide an extensive array of allied health services supporting patients in recovery and the prevention of ill-health. MW's initial pilot takes place in Dandenong, one of the most deprived areas of Melbourne.

Monash Health's 15,000 staff work at more than 40 sites, providing over three million occasions of service, admitting more than 238,000 hospital patients, and handling more than 206,000 emergency presentations.

Monash Health was an early adopter of readmission prevention programs. These programs include:

- Complex continuing care (CCC) program—this program has reduced avoidable admissions from chronic disease such as cardiac failure and psychosocial health issues by providing self-management and supportive programs[1]

[1] http://www.monashhealth.org/page/Chronic_disease_services_HARP_CDM—last accessed: 31-Aug-2017.

- Hospital in the Home (HITH) program—this program has reduced admissions for management of common infections like cellulitis and pneumonias by administering iv antibiotics in the patient's home
- Community services link with care planning, team care referrals (EPC) available to GPs and primary care through Medicare funding
- In some settings, telehealth programs were provided for patients with complex conditions such as renal disease

HealthLinks Chronic Care (HLCC) is a funding pilot that forms part of the Victorian Department of Health and Human Services' approach to public hospital funding reform and its objective of delivering person-centered and integrated care.

It is generally well accepted that integrated community-based care and active management can result in better outcomes for people living with chronic conditions and may help reduce their need for inpatient care. However, the overlapping role and responsibility of ambulatory and inpatient care services, separate funding streams and models of care, as well as activity-based funding for acute care, can create a barrier to integrated care.

The HLCC funding model has been designed as a first step in removing the funding barriers to delivering alternate models of care for patients with complex chronic care needs. Health services will be given the flexibility to use projected inpatient activity-based funding to design packages of care around the needs of these highly complex patients. Packages will be inclusive of inpatient care and can include services that reach beyond the traditional hospital walls, therefore delivering a more comprehensive and integrated mix of services.

This approach, which uses a capitation funding model, is designed to promote innovative models of care that produce better outcomes for patients, at no additional total cost to the public health service system. Health services will benefit from any cost savings achieved through service innovation and efficiency.

Overtime, it is anticipated that patients at high risk of readmission to hospital will be more accurately identified and provided with targeted active management, thus reducing their use of unplanned inpatient care. It is recognized that in delivering this new model, enrollees may consume more planned and community-based care. This shift will not increase the overall cost of the individual patient's care if their use of unplanned inpatient services can be reduced.

Independent, external evaluators will be engaged for the duration of the trial and will assess the impact of the trial at the system level. Health services may seek to engage external evaluators to assess the impact of the interventions/changes they deploy at the local level.

In the first phase, Monash Health is only one of a small number of selected health services invited to consider participation.

5.5 Falling Between the Silos of "Evidence-based" Care

Why does Monash Health (and possibly Ireland) have so many patients falling between the silos of "evidence-based" disease care, necessitating the need to attend ED with potentially avoidable hospitalizations?

The following clusters of patient characteristics have emerged as possible reasons for avoidable ED use:

- Unstable journeys with a wide variety of stresses and tipping points
- Poor social support including partner, family, and/or community
- Poor engagement with supportive services
- Historical patterns of seeing ED/hospital as the place for primary care
- 24-h universal access to ED
- Younger people with substance abuse and medical consequences
- Older people with a combination of multiple morbidities, frailty, and/or social isolation
- Those struggling with self-management and the ability to anticipate and plan ahead
- Poor access to healthcare due to lack of transport, poor housing and limited finances, and cultural and linguistic barriers

5.6 PaJR: The Principles

PaJR Care Guide conversations (***outbound and inbound***)—mainly by telephone—are recorded and analyzed using predictive analytics. Conversation sensemaking takes place on a real-time basis. Clinician coaches provide mobile, anticipatory care and initiate home visits and care coordination in response to the current conversations and alerts generated by the PaJR algorithm. This is a learning system that adapts as the service develops.

PaJR developed its technologies to improve care management with providers who offer outbound calls to support patients after they have been discharged from hospitals or who have been identified as being at risk of hospitalization (Fig. 5.3).

Funding for the Irish study was initially through the National Digital Research Centre to develop a person-centered information technology approach to avoidable admissions based on a complex adaptive chronic care conceptual framework developed previously [18]. A team comprising a clinician, two academic computer scientists, a project manager, two postdoctoral students, and two industrial partners developed and tested clinical algorithms on summarized outbound conversations with the potential to apply machine learning to these conversations. The intention

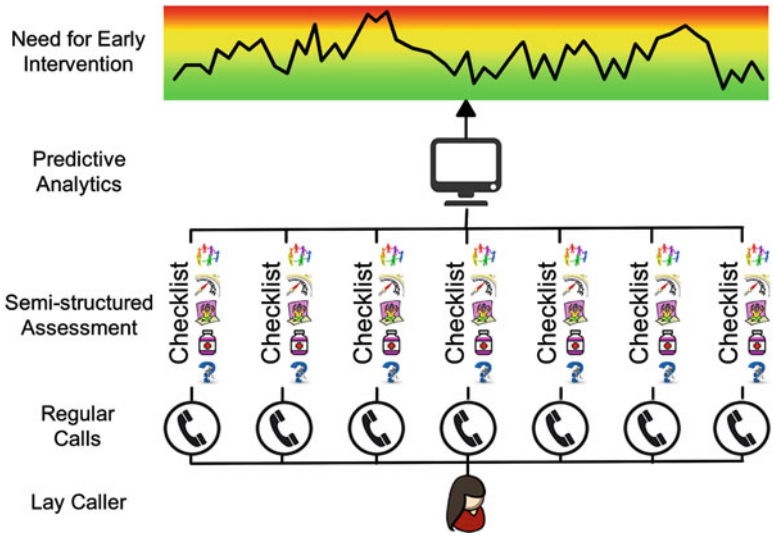

Fig. 5.3 PaJR design principles

was to identify patterns in the conversations which would predict deterioration leading to hospital admission.[2]

The MW innovation connects "big data" with "personal data." MW identifies eligible adult (>18 years old) patients via a predictive analytics model allowing innovative use of hospital inpatient funds. Patient care profiles from routine care—primary and community care, social care, and hospital data (with addition of other big data over time)—are linked into the MW data system (Fig. 5.4). These almost real-time data are used in the context of conversations to stabilize journeys where possible and anticipate future risks.

5.6.1 Clinicians in IPCC and MW

Both IPCC and MW utilized care guides to listen, converse, and use these conversations to "predict deteriorations." The IPCC clinicians/nurses and allied health professionals triaged and guided patients to appropriate services. Monash-Watch Health Coaches, who are clinicians including nursing, physiotherapy, and occupational therapy located inside the Monash Health hospital system, provide this role in an innovative and adaptive manner. They provide home visits, accompany patients to hospitals or GPs, and facilitate transport, financial, and housing support

[2]https://www.siliconrepublic.com/start-ups/patient-journey-record-taps-into-global-health-tech-demand—last accessed 31-Aug-2017.

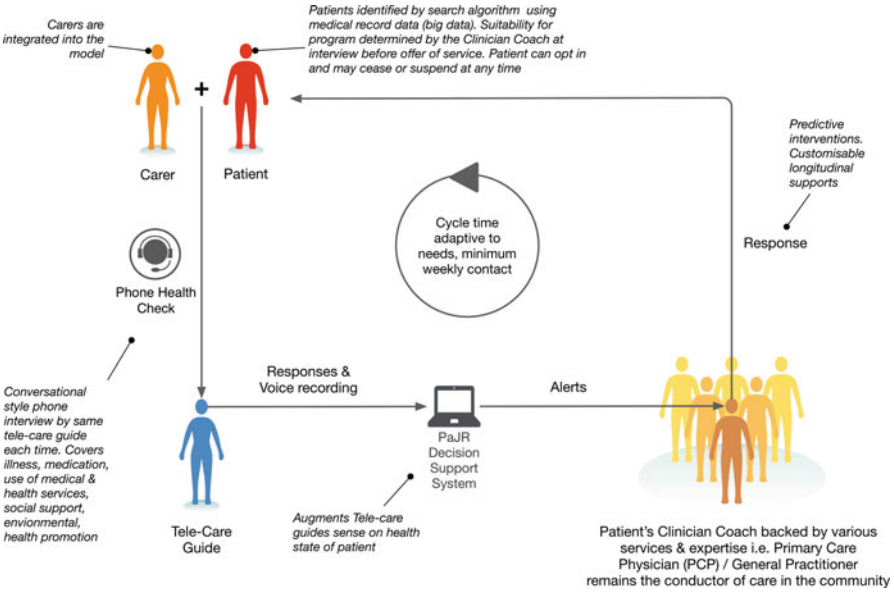

Fig. 5.4 MonashWatch incorporating PaJR system—customized patient service. Connecting "big hospital data" with "personal health experience data." These almost real-time data are used in the context of conversations to stabilize journeys where possible and anticipate future risks

in an open-ended responsive manner. Care guides are supervised by coaches to help patients planning with their "next step." In addition MW Health Coaches provide essential communications especially when prompt advice is needed from within the hospital system which is hard for GPs, let alone, for patients to obtain. The leading brokerage role of coaches aims to connect GPs, hospitals, and community care in an anticipatory manner well in advance of patients reaching a tipping point.

5.7 Complex Adaptive Care and Feedback Loops: Preliminary Analysis from Pilot Studies

This analysis aimed to compare the first data (616 calls) from the IPCC and MW pilots and to provide feedback to adjust the processes for the MW rollout.

A complex adaptive systems intervention recognizes that continuous adaptation is needed based on ongoing feedback. In particular, we aimed to adapt the intervention based on the following questions:

- What profiles emerged from the PaJR conversations?
- How do MW patients compare with IPCC in their concerns, their expressed significant symptoms, and their perceived urgency of problems (translated into alerts)?
- Are different dynamics emerging? What do they tell us about the PaJR system and the different groups? How might these influence the likely responses and interventions?

5.7.1 Using Qualitative and Quantitative Data of IPCC and MW PaJR Calls

The first 616 calls from MW and IPCC pilots were analyzed using descriptive statistics. Variables included self-rated health (SRH), disease symptoms of concern, and psychosocial and environment concerns. Which combination of variables was associated with triggering red or pink alerts?

Red alerts are those that require clinical assessment either immediately or within a specified time within 24 h. Features that trigger a red alerts include chest pain, severe pain of any nature, a fall, a mental health or housing crisis, and recent attendance at the ED.

Pink alerts are those that do not require prompt attention; features that trigger a pink alert include persistent diagnosed pain, other chronic symptoms, ongoing concerns about sleep and mobility, ongoing need of social support, and financial and housing issues.

5.7.1.1 Findings

The IPCC group were older from a rural environment but had similar frailty levels to the MW group. Care guides making calls in the IPCC were all local Irish women.

The participating MW cohort were all English-speaking but had a very diverse ethnic background coming from Asian, West and East European, and Middle Eastern countries. The MW care guides and coaches were all from the local community, but did not mirror the diversity of the MW cohort.

Reported concerns and self-rated health reports were similar between the two groups with no significant differences. Symptom patterns were different with significantly more pain and depression reported in the MW group. Statistically more psychosocial and environmental alerts were reported per call in the MW group compared to the IPCC group (Table 5.1).

Particularly striking was the preponderance of "not coping," pain, and depression in calls to the MW group. In the first 3 months, none of the IPCC patients reported "non-coping." The rate of problems reported per call in "MW non-coping calls" were ($n = 48$):

Table 5.1 Comparing PaJR Profiles in IPCC and MW cohorts at 3 months

	IPCC	MW
No of participants	52	48
Recruitment	GP invitation	Outreach by hospital
Profile difference	≥1 ward admission in the last 12 months	Prediction of ≥3 ED or ward admissions in the next 12 months
Uptake rate	90%	60%
Dropout rate	5%	3%
Number of calls	616	616
Time	5 months	4.5 months
Age	76 (67–85)	65 (31–91)
Self-rated health average	Fair-good	Fair-good
Alerts per call (problems identified)	Mean 0.45, median 0, SD 1.06 var. 1.12, skewness 2.24 range 0–4	Mean 2.70, median 1, SD 3.62 var. 13.09 skewness 1.84 range 0–21
Red alerts 0–4 h⇒24	28% of calls	25% of calls
Requiring attention		
Most common "symptoms of concern" reported	Breathlessness and fever/feeling ill	Pain and depression
Calls reporting "Not coping"	none	48/616 calls (8%)
Patients reporting "Not coping" in 1 or more calls	none	19 out of 48 patients (40%)

- Medication problems 23/48
- Healthcare access/use problems 21/48
- Social support and social services 57/48
- Environmental—housing, finances, and transport 24/48
- Self-care and functional problems such as nutrition, sleep, etc. 66/48

The following two cases illustrate the different "type" of patient in the IPCC and MW groups.

Kevin[3] (see Table 5.2). Kevin is a 79-year-old bachelor who lives next door to his sister Mary who is 81 and a caregiver to Kevin and her husband who has dementia (but she is quite fit). Kevin is a retired farm worker in County Kildare. He has chronic lung disease, diabetes, heart disease and peripheral vascular disease, sciatica, and recurrent chest infections. Kevin at times forgets about his treatment and appointments. His GP has a very large rural practice but has been Kevin's GP for 50 years.

[3]The names of the patients and timelines of their journeys have been altered to conceal their identities.

Table 5.2 "Kevin": a "typical" Irish patient's conversational journey

15/06/12	My breathing has improved since stay in hospital
16/06/12	My throat feels better and generally feels better than yesterday
17/06/12	I feel 2–3 out of 5 today and will never be 100%
20/06/12	Breathlessness will be more or less the same. Not likely to get much better than is at the moment
21/06/12	My chest is reasonably today 80%; says as 3/5 is as good as it gets
22/06/12	Ankles are better today than yesterday, 0 swelling, didn't go to or ring the GP as asked; Kevin's sister seemed to think P was confused that he may have missed an appointment. That was why I had asked him to speak to the GP
28/06/12	Kevin didn't feel great on Thursday. My chest can change very quickly, I didn't want to take another antibiotic but have to. Stomach is beginning to settle down and I went for a short stroll today
29/06/12	I still have pain in the ankle when walking, but pain relief is working at night; I am more breathless in the morning and this improves as the day goes on
30/06/12	My health will remain at 80%
01/07/12	Fine today and I went to town
04/07/12	Legs are sore today especially when walking. Back to the hospital tomorrow for a follow-up and hopefully will get them sorted
06/07/12	Consultant was happy with my chest yesterday and prescribed pain relief for his leg and a scan in 6 weeks time
08/07/12	Chesty this morning, but the leg has improved not as sore when walking
12/07/12	Chest is still the same
14/07/12	Legs are 3, and chest is fine today
18/07/12	Pains in the leg when walking
20/07/12	Chest is "middling" today as he puts it. Going to the GP this afternoon to get a prescription and have a listen to the chest
25/07/12	A bit of a cough, not too breathless, my GP put me on steroids and antibiotics

Kevin's health journey demonstrates an ongoing unstable dynamic of managing his conditions. Kevin, in the first 3 months of the study despite many fluctuations in his health, remained cheerful and accepting of his health condition.

Mick (see Table 5.3). Mick is a 59-year-old, of British descent who lives with his wife in a rented apartment in an estate in inner-city Dandenong, one of the most deprived areas in Melbourne. Some major industries have collapsed leaving a very high rate of unemployment with an influx of refugees and immigrants with low socioeconomic backgrounds. Mick began drinking when he lost his job 15 years ago and has relapsed on many occasions. His relationship with Betty is strained by his drinking and her cancer makes him feel very guilty. His chronic pain is related to pancreatitis, gastritis, liver disease, back pain, and depression. Mick has many fluctuations in his health related to drinking and decompensated depression. His GP is part of a large corporate primary care practice which has been set up within the past 12 years.[4]

[4]Corporatization is becoming a dominant model of Australian medical practice.

Table 5.3 "Mick": a "typical" MW Australian patient's conversational journey

30/12/16	I really like to know what's going on with me and what's causing all my pain. The doctors aren't telling me anything
03/01/17	My pain taking relief is holding at 3 to 4
06/01/17	I was concerned about tummy neck pain and headache last Sat
10/01/17	Worried about why and the fact that I didn't eat at all last Sat
11/01/17	"I'm in trouble I want a drink" (Mick is an alcoholic and had a drink last night for the first time in some months)
10/01/17	"Can I tell you something—I've had enough. Enough of the pain and everything." "B tries to help but doesn't understand." "I can't eat a big meal I'm not even hungry." Mick is worried about B who is a breast cancer patient who had a mastectomy and is currently having a skin test
13/01/17	Sat. Tummy sore but not sick. I couldn't help myself and started drinking again
17/01/17	Got drunk again
25/01/17	Crisis took him to hospital
02/02/17	Released from hospital yesterday and didn't feel well. I thought I was in for detox and to start medication. I was in for pancreatitis, but they didn't address alcohol issue. Drug and alcohol appoint on 14/2, but I may be in any state by then. Drug and alcohol said if Mick could get him to present to the hospital then they would start detox and meds. MB confused as to why they released him. Mick took a taxi home by himself

5.8 Discussion

Despite very different settings and risk profiles, self-rated health and red alerts that require attention (mostly GP care) were very similar in the MW and Irish cohorts. Pink alerts were statistically more numerous in the MW cohort with psychosocial/environmental comorbidities and more frequent in the IPCC cohort affected by disease multimorbidity.

The two communities in which PaJR has been implemented are very different but have some surprising similarities. Recruiting patients from a general practice setting might select a more socially stable group, while patients with pain and alcoholism may present more readily to hospital emergency departments.

Despite poverty in rural Ireland, there may be more social cohesion within the community which provides a social safety net, but this may not exist in the inner city with a highly fluctuating population structure. As our recruiting occurred through primary care, we may not have tapped into the cohort with different needs presenting to ED of a hospital.

The use of ED for short-term crises related to a cluster of pain, depression, and drug problems in MW—as illustrated by Mick's case—is evident in the pattern of admissions and length of stay. The MW cohort has a distinct pattern of repeated ED short stays. The predominant reason for these short stays is "pain" in the cluster of cluster of "pain, depression, and alcohol/drug problems." Figure 5.5 illustrates the persistence of a pattern of frequent 1-day admissions (known as ED short stay admissions) in the progress of MW at 6 months related to the cluster described.

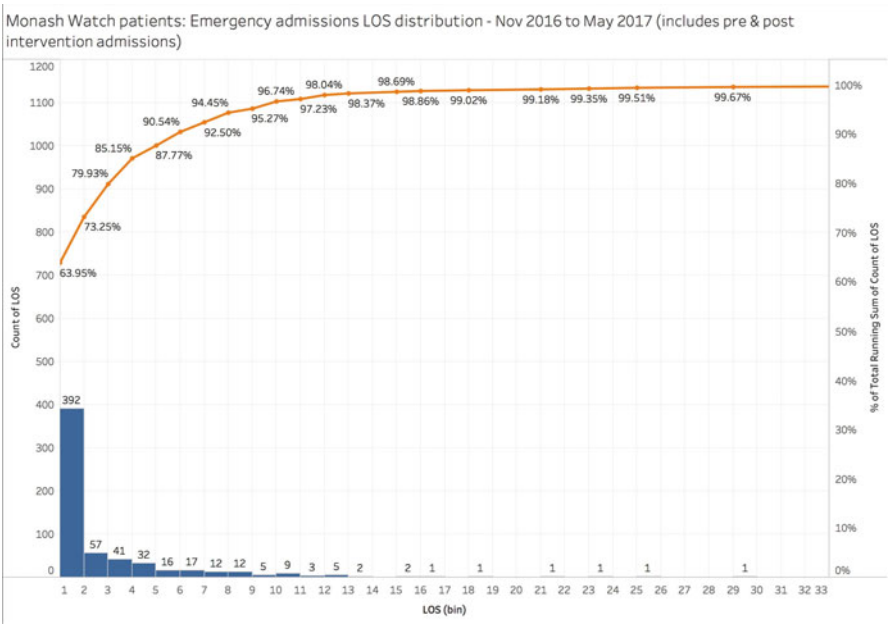

Fig. 5.5 Length of stay and number of admissions in MonashWatch patients. Length of stay and number of admissions in MonashWatch patients (≥1 overnight stay in hospital either in the ED department or admitted to a ward). Admissions are frequently for ED short stay at 6 months of MonashWatch. 33/148 patients had 33 admissions. Not all admissions are avoidable and indeed may reflect optimal care

Nevertheless, MW also had older patients similar to the IPCC with longer LOS, who presented with typical patterns of breathlessness and poor health.

Because PaJR is a practical system, not a research instrument per se, its value lies in identifying the unmet needs of patients. The patterns described in the IPCC and MW patients are different, which raises hypotheses for further research and investigations. As a complex adaptive systems tool, it does adapt to different populations in different contexts. The findings reported here confirm PaJR's utility and adaptability; there is sufficient evidence support continuing implementation of PaJR type approaches.

Conversations that tap into interoception and support resilience are the cornerstone of "helping." Trust in care guides is essential, and potential limitations relate to the use of a common language and perhaps culture.

The use of care guides who are trained to use the system under supervision, but are not health professionals, has worked in both locations. However, some authorities are cautious about the risks of employing a nonprofessional "lay" workforce, in particular legal implications if serious problems are missed.

However, the PaJR system is an outreach system beyond existing formal health services. It exists where there is a vacuum in unstable complex patient journeys.

The central intervention is conversations and self-report, not the diagnostics of new complaints. Lay care guides are supervised by professionals, and the PaJR system has "embedded" expert knowledge and decision support. The low dropout rate suggests that conversations tap into interoception and support resilience—the cornerstone of "helping." Trust in care guides appears to be achievable where there are a common language and cultural sensitivity.

The role of coaches in MonashWatch in a supervisory role and the transparency of audiotaped calls addresses these risks. The coaches are the first line of the response arm and make it possible for the lay persons to be care guides. The brokerage role of the coaches while not unique is highly innovative and adaptive. The use of informatics and almost real-time analytics allows for rapid feedback loops and anticipatory activities.

Ultimately the success of any service utilizing PaJR approaches to identify need depends on what resources and services are available to meet these needs.

Providing adaptive medical care for chronic disease in the face of an aging population is challenging, yet compared to addressing broader psychosocial and economic health determinants, health and aged care services are able to manage these challenges. MW has identified considerable unmet needs in the care of younger- and middle-aged adults in pain, depression, and substance use clusters which are linked to unemployment, poverty, and poor social cohesion.

5.9 Conclusions

The PaJR system identifies needs that benefit from being met in a timely fashion. In deprived diverse communities, interventions in particular need to address the social determinants of health beyond "disease management."

Hospital avoidance schemes using a complex adaptive and resilience-focused systems approach such as PaJR are demonstrably appropriate in at least two different settings, provided they are highly adaptive in their responses. Self-care support in PAH improvement requires varying levels of clinical, personal, appraisal, informational, and practical support as illness becomes unstable.

Operationalizing the biopsychosocial model in two different settings, we found two distinct profiles. A younger, more depressed urban cohort suffering from pain and social and environmental problems, and an older rural population affected by social isolation and typical chronic disease morbidity.

Increased utilization of a dynamic systems understanding through conversations recognizes the importance of personal health perceptions in critical health state transitions [19]. Talking to individuals about their health and actively understanding their meanings of signs and symptoms in the context of their personal family, social, and health networks would seem to be a core activity in improving preventable admissions.

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The Journey

The journey to MonashWatch has evolved from the networking among multiple actors with the emergence and confluence of different streams of experience, data, knowledge, and, hopefully, the "getting of wisdom." This journey is a response to the changing nature of population aging, health and illness, societal changes, and the dynamics in the political economy of healthcare.

Carmel's Journey. I first came to the nature of chronic illness because of the almost fatal consequences of the medical management of my healthcare. I experienced the effects of lack of time and effort taken to understand my condition by one group of medical practitioners, the exemplary care by another group, and (perceived) lack of support from general practitioners, to serious illness. As a practicing general practitioner, in much better health, I returned to this topic, because I found that chronic care was difficult and time-consuming with intense personal demands. This forced me to question the processes and directions of my and health systems efforts. I began a 25-year journey to understand and improve the care of chronic illness using complex systems theories, because the linear disease-based evidence did not fit my experiences. Complex systems theories have developed from insights with respect to human behavior, human values, evolutionary biological systems, and statistical physics of the early complex systems theorists. These seemed more relevant to chronic illness.

This drive for innovation with new clinical approaches inspired by complex adaptive systems (CAS) theories found synergies with my collaborators at various junctures: Joachim Sturmberg in improving primary care as complex systems, Keith Stockman and Donald Campbell from Monash Health with their wealth of experience in user-centric design and health service innovation in hospitals, and Carl Vogel, Lucy Hederman, and Kevin Smith from the perspective of information theories, natural language processing, and computer science. Taking a broad view of health and healthcare related to human systems innovations in nonlinear CAS requires a range of "complex bundles" of innovation from a widely distributed knowledge base based on information from individuals, families and communities, services, and populations.

My journey through complexity continues to encounter the reductionist analyses and simplistic (off-the-shelf) solutions that are always attractive to funders and managers as mechanisms to "control" uncertainties. Accounting for the human dimension (experience) of health and systems requires three overarching principles: a fundamental commitment to emancipation through practical action, critical awareness rather than conventional "wisdom," and methodological pluralism. Systems thinking in general seeks to understand an issue as a "gestalt of its parts". During

my career, there has been a gradual widening of understanding and application of these principles in health; however, political expediency and reductionism continue to undermine progress.

Life is Precious Because it is Precarious:
Individuality, Mortality and the Problem of Meaning
Tom Froese [20]

Take-Home Message
Supporting complex health journeys through conversations using lay care guides and an adaptive systems approach is feasible in at least two very different settings and patient groups. This approach identifies problems that are amenable to intervention but also some that may be challenging to solve with existing resources.

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