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Chaplains Work in Primary Care

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ABSTRACT

Health is holistic, but health services are often not. Primary care is the first point of contact for patients in the UK, and at least two in every three present with complex bio-psycho-socio-economic issues. In Scotland, the Community Chaplaincy Listening (CCL) service was created to see if chaplains could help. CCL involves specially trained chaplains listening to patients referred to them by general practitioners (GP) for spiritual support. Between 2018 and 2019, 143 people used CCL and completed baseline and post-discharge outcome measures. Mean Scottish PROM scores rose from 7.94 (\pm 3.4) at baseline to 12 (\pm 3.5) post discharge, a statistically and clinically significant rise of 4.06 (95% CI, 3–5.12), $t(50) = 7.7$, $p < 0.0001$, $d = 1.08$. The improvement was seen whether patients self-described as religious, spiritual, both, or neither. Health-related quality of life outcomes were mixed but patients referred to the service scored some of the lowest baseline EQ-5D-3L scores ever seen in the literature. Together these results suggest that CCL worked in primary care, especially for patients historically considered “difficult to treat.” Limitations of the study are considered alongside implications for commissioners and service developers.

KEYWORDS

Chaplain; measurement; outcome; primary care; quantitative

Introduction

Since the 1970s, the World Health Organization has recognised the spiritual dimension as an integral component of healthcare (Winiger, 2020). However, this recognition has been difficult to operationalise (Winiger & Peng-Keller, 2021). One of the reasons for this is that public engagement with religion has declined in the Western world as interest in secular and alternative views have grown (NHS Education for Scotland, 2009). Chaplaincy has recognised that the spiritual needs of the local population are changing, and in 2018 the UK National Health Service (NHS) recruited its first secular chaplain (Brown, 2018). However, the majority of NHS staff & patients still associate chaplaincy with religion (Ryan, 2015), which means people suffering spiritually with sub-clinical,

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chronic, or non-medical distress, the types of issues that chaplains are best equipped to help with (van Dijk, 2021), don't get the support they need because spiritual distress is not seen as such. This is further problematic because there is evidence these people instead present later with more intractable and costly but easier to recognise mental and physical health problems (Hall & Powell, 2021; Jakucs, 2021).

In other words, a vicious cycle is perpetuated: the failure of health and social care services to recognise and manage spiritual distress results in this distress manifesting as more recognisable but also more debilitating problems, which clinical staff then need to prioritise, possibly at the expense of others' spiritual distress, and so on (Royal College of Physicians, 2020). Primary care chaplains could help break this cycle (Bunniss, Mowat, & Snowden, 2013; Gibbon & Baldie, 2019; G. W. Macdonald, 2018), but in the main health and social care colleagues such as GPs, nurses and social workers don't know how, when and why to refer patients to chaplains (Damen, Schuhmann, Leget, & Fitchett, 2020). This paper contributes by measuring the impact of a chaplain listening service on people referred to them in primary care. First, it examines the current evidence for chaplains working in primary care, then introduces community chaplaincy listening (CCL), the intervention under study.

Primary care and chaplains

Primary care services are the first point of contact in the UK healthcare system (NHS England, 2021). People register with their local practice and then attend when they are ill. Attendance is free for the patient, and there is approximately one medical generalist, a "general practitioner" (GP) for every 2000 patients. Primary care services in the UK are regularly described as in danger of being overwhelmed due to ever increasing demand (Hobbs et al., 2016), and that was before the pandemic. A recent survey found UK GPs worked 11-h days, undertaking an average of 37 consultations, nine more than the nationally agreed safe limit (Merrifield, 2021).

Complexity of presentation has also increased, with more than two in every three consultations rated as "complex" by GPs (Merrifield, 2021). The term "complex" here refers to patients with concomitant comorbidities or bio-psycho-socio-economic (Edwards & Loprinzi, 2017) issues. McSherry, Boughey, and Kevern (2016) suggested that people suffering spiritually can present with physical and mental distress, often expressed as addiction or obesity, associated with loss, isolation and loneliness. G. W. Macdonald (2018) broadly agrees with this and also includes relationship issues, job and financial problems (see Box 1). G. Macdonald (2017) refers to these presentations, that are usually accompanied by generalised loss of wellbeing, as "modern maladies." It is people presenting with these issues that may benefit from healthcare chaplaincy in primary care.

Box 1. Issues patients present with in primary care that chaplains have helped with according to G. Macdonald (2017; G. W. Macdonald 2018) and McSherry, Boughey, and Kevern (2016).

Depression; Anxiety; Relationship breakdown; Job issues; Bereavement; Self-image problems; Loss of well-being; Guilt; Negative life experience; Financial issues; Loss of Identity; Family breakdown; Loss of confidence; Addiction; Obesity; Loss of: hope, self-confidence, self-efficacy, and sense of purpose and meaning.

Healthcare chaplains in UK work primarily in hospitals (secondary care), or hospices (tertiary care), often in palliative care or advocacy, although their roles can be very diverse. Chaplaincy has also had a presence in primary care for the last 20 years (Giffen & Macdonald, 2020), but it is not the norm. This could be revisited because there is a small but growing evidence base showing that chaplains can be effective in primary care (Kevern & Hill, 2015; G. Macdonald, 2017; G. W. Macdonald, 2018)

For example, Kevern and Hill (2015) found a relationship between chaplain interventions and mental wellbeing. Further investigation (McSherry et al., 2016) showed that these chaplains had helped people suffering loss: loss of hope, self-confidence, self-efficacy, and sense of purpose and meaning. Another study showed that patients felt they had a more positive outlook, were less anxious and felt more in control after seeing primary care chaplains (Snowden & Telfer, 2017). GPs anecdotally reported that being able to refer patients to chaplains had mitigated their need to prescribe anxiolytics, as well as preventing unnecessary onward referrals to psychiatric services (Snowden, Gibbon, & Grant, 2018). Patients feeling able to “*talk about whatever was on their mind*” was central to these outcomes (Snowden, Telfer, Kelly, Bunniss, & Mowat, 2013a), and Lobb, Schmidt, Jerzmanowska, Swing, & Thristiawati, (2018) showed that chaplains are good at facilitating this.

Together these results begin to show there may be something important about skilled listeners giving people the space to tell their story. It has the potential to break the cycle of “loss,” followed by primary care attendance, diagnosis, prescription, prescription fail, return of “loss,” return to primary care, and so on. G. W. Macdonald (2018) provided further evidence for this by showing that people with long term conditions referred to chaplains in primary care did not reattend their GPs as regularly they had done previously. This positive impact on GP workload was also found by Snowden et al. (2019), who also found that because chaplains could help GPs with some of their most “difficult to treat” patients, that this in turn helped raise team morale and prevent GP burnout.

There is increasing evidence that chaplains in primary care can help with the issues in [Box 1](#) as described by Giffen and Macdonald (2020) and McSherry et al. (2016), but it remains unclear how people who could benefit from the service could be identified, or what the potential benefit may be. This information will be key because service commissioners will need evidence to support any proposed change to primary care. For example, the role of religion and spirituality remains unclear. Do chaplains have more success when a patient self describes as spiritual or religious, or do chaplains have the same impact regardless of faith/belief? How could someone suffering from “loss of meaning” be identified?

In other words, there is substantial promise for the strategic deployment of chaplains in primary care, but commissioners need to better understand the process and value of the service. Hall and Powell (2021) summarise the key issues when stating that a more structured method of targeting spiritual care would benefit the patient, the health service, and the economy. This study contributes to that agenda.

The intervention: community chaplaincy listening

Community Chaplaincy Listening (CCL) is a listening service linked to general practice in health care centres in Scotland. It involves chaplains meeting with and listening to

people who have been referred to them, most commonly by their GP (Mowat & Bunniss, 2012). The service is delivered in the same health care centre that the GP works in. Referred patients meet with the chaplain who explains the service to them and answers any questions. The patients then have as many sessions with the chaplain as they need to tell their story, consider the issues they are facing with the aim of working towards a sense of resolution or peace with what is currently happening in their life. Sessions routinely last 50 min and patients are free to discharge themselves from the listening service at any time, without explanation (Gibbon & Baldie, 2019).

Chaplains undergo dedicated training to become listeners. They have four intensive days of face-to-face theory and reflection followed by six months' probation supervised by a CCL trainer, a specially trained chaplain mentor. Supervision is at least monthly, but after six months, if signed off by the mentor as competent then the listener's supervision reduces from monthly to three-monthly, although support is always available if required. Detail of CCL training and CCL supervision is here.¹

Study design

For the research to have the greatest impact CCL needed to be systematically evaluated in the most robust manner possible. The “gold standard” randomized controlled trial was difficult to justify because there was already persuasive evidence that chaplains provide meaningful support for people in spiritual distress in primary care. Potentially depriving someone of that support for the sake of methodological rigour would be unethical. One potential solution would have been to randomize participants to see a chaplain or a counsellor, for example, thereby not only identifying if chaplains were effective, but also establishing any potential unique contribution. The major problem was that was a resource intensive option, and funding was not available. Arguably, the next most rigorous design after RCT is a prospective, multisite, paired-sample “before and after” study to examine change over time in a single cohort (Greenhalgh, 2010), and so that was the method chosen to quantify the impact of healthcare chaplains in primary care on people in spiritual distress in Scotland.

Aim

To evaluate the impact of Community Chaplaincy Listening on patients in primary care.

Objectives

Articulate the difference CCL makes on patient outcomes.

Understand the relationship between the quality of the CCL encounter(s) and patient outcomes.

Hypotheses

1. Patients will record higher scores on the Scottish PROM after CCL intervention.
2. Patients will record higher scores on Health-Related Quality of Life measures after CCL intervention.

3. The patient experience of CCL will be associated with its outcome.
4. There will be no difference in outcome whether patients self-describe as religious, spiritual, both or neither.

Method

Prospective, repeat measures, paired-sample cohort study.

Participants

Inclusion/exclusion criteria

Project participants were patients who attended the CCL service and who consented to participate in the study. The study exclusion criteria specified children under 16, and people unable or unwilling to consent, such as people with advanced cognitive issues.

Ethics

Conducting research involving NHS patients requires NHS ethics approval. This UK-wide system means ethics applications can be reviewed by any UK Research Ethics Committee. Ethical approval to undertake this study was awarded by Southeast Coast—Brighton and Sussex Research Ethics Committee (17/LO/0634) in 2018. Permissions were also obtained from all participating Research and Development offices.

Measures

The Scottish PROM

The Scottish Patient Reported Outcome Measure (PROM) is a five-item measure of the outcomes of spiritual care as delivered by a chaplain (Snowden & Telfer, 2017). It has five-point Likert responses ranging from “none at all” to “all the time,” to items asking how the patient has been in the last two weeks in relation to: peace, control, outlook, anxiety, and honesty. Each item is scored from zero to four, with the anxiety item reverse scored. Total PROM scores are calculated by adding the individual item scores and therefore range from zero to twenty (Snowden, Tan, & Karimi, 2021). There is also a free text box for elaboration should the patient wish to (Snowden & Telfer, 2020). See Table 1.

Health Related Quality of Life: EQ-5D-3L

Health Related Quality of Life refers to self-perceived impact of a health-related condition and how it impacts on a person’s ideal physical, mental and social wellbeing (Van Wilder et al., 2019). The EQ-5D-3L is a standardized five-item measure used quantify Health Related Quality of Life (van Reenen & Oppe, 2015). This version of the EQ-5D is referred to as 3L because it has three levels of response to each item (1. no problem, 2. some/moderate problem, 3. severe/worst possible problem). The five items relate to: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each item is weighted according to local population norms, and total scores range from zero

Table 1. The Scottish PROM items with associated scores for responses to different items and categories of response.

This short survey asks you to think about how you have felt in the last two weeks. Please tick one box for each question.

In the last two weeks I have felt:

	None of the time	Rarely	Some of the time	Often	All of the time
I could be honest with myself about how I was really feeling	0	1	2	3	4
Anxious	4	3	2	1	0
I had a positive outlook on my situation	0	1	2	3	4
In control of my life	0	1	2	3	4
A sense of peace	0	1	2	3	4

Total PROM scores are calculated by adding up the five individual scores, giving a possible range of zero to 20.

Table 2. The patient experience of the Scottish PROM.

This short survey asks you to think about your experience with the chaplain. Please tick one box for each question.

During my time with the chaplain I felt:

	None of the time	Rarely	Some of the time	Often	All of the time
Understood	0	1	2	3	4
I was able to talk about what was on my mind	0	1	2	3	4
I was listened to	0	1	2	3	4
My faith and/or beliefs were valued	0	1	2	3	4

(equivalent to death) and one (equivalent to full health). The version used in this study also included a visual analogue scale (VAS), consisting of a vertical scale with zero at the bottom and 100 at the top. Participants circle the value indicating their general health at that moment. EQ-5D was chosen for this study because it is the most widely used measure of health-related quality of life in the world, and it is free to use for non-profit organisations. Data generated from EQ-5D-3L scores allow a wide range of health states to be quantified and compared. For example they are used to calculate Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs) in economic analyses of different interventions (Van Wilder et al., 2019).

The experience of CCL

Measuring the experience of CCL involved four Likert style questions administered on discharge from the service. The four questions focus on the patients experience of the chaplain's capacity to: listen, facilitate the person to be able to talk about what is on their mind, understand them, and value their faith/beliefs. These questions generally accompany completion of the "post intervention" Scottish PROM, and originated in the same concept analysis of chaplain activity underpinning the initial construction and validity testing of the PROM (Snowden & Telfer, 2020). See Table 2.

Self-description of religion or spirituality

The demographic element of the survey asked the participant to give their age, gender and to self categorise in one of four options: religious, spiritual, both religious AND

spiritual, or neither. This allowed for the creation of the subgroups needed to test whether there were any differences in benefit according to faith/belief groups.

Analytic Plan

All hypotheses were tested by comparing the average scores of one group or subgroup against the average scores of another to see if there was (a) a significant difference (hypotheses 1, 2, 4) or (b) a significant relationship (hypothesis 3) between the group scores (Brace, Kemp, & Snelgar, 2009; Field, 2005). Significance here means “most likely to be true,” and by convention this likelihood is agreed to be 95%. Another way of thinking about this is that the probability of getting a false result by mistake is 5%, or 1 in 20, written by convention as “ $p = 0.05$.” This convention of $p = 0.05$, also referred to as “alpha,” means that for every 20 times the same experiment is repeated, 19 out of every 20 would expect the same result.

However, for that conclusion to be valid, the study data need to meet certain assumptions first. The following paragraphs describe the assumptions that need to be checked for each individual hypothesis test. Each then concludes with a decision about which test would be the best to use based on the outcome of those checks (M. Lund & Lund, 2022b). A sample size calculation concludes this process, given it depends on assumptions as well, such as the number of hypotheses tested on the same sample, and the estimated likely effect size of any intervention under study. The purpose of the sample size calculation is to ensure that a) the study is likely to answer its hypotheses whilst b) inconveniencing the least amount of people possible.

1. *Patients will record higher scores on the Scottish PROM after CCL intervention.*

First, the data were checked for outliers, and the distribution of the differences in the PROM scores between the two related groups were checked to ensure they were approximately normally distributed. The paired-samples t-test was then used to determine whether the mean difference between paired observations was statistically significantly different from zero (M. Lund & Lund, 2017).

2. *Patients will record higher scores on EQ-5D-3L after CCL intervention.*

This hypothesis was also tested using paired sample tests following the same assumption tests as hypothesis 1. This hypothesis consisted of two independent tests, one of the EQ-5D-3L scores, and the second on the visual analogue scale (VAS) scores.

3. *The patient experience of CCL will be associated with Scottish PROM scores.*

Monotonicity was checked using scatterplot and then parametric or non-parametric correlations would be explored to test the relationship between the PROM scores and the self-reported experience of the intervention (M. Lund & Lund, 2022a). A significant correlation would show that there was a relationship between the quality of CCL intervention and the subsequent outcomes.

4. *There will be no difference in outcome according to whether patients self-describe as religious, spiritual, both, or neither.*

Four categories were constructed for people who described themselves as religious, spiritual, both or neither. Assumptions were tested as per hypotheses 1 & 2, then one way ANOVA was used (A. Lund & Lund, 2015) to determine whether any changes in Scottish PROM scores were significantly different according to how people described their faith/belief.

Sample size calculation

Because hypotheses 1, 2 and 4 used the same dataset to run a total of four tests, a Bonferroni correction was made to adjust alpha, which as discussed above is set by convention at 0.05, so alpha was divided by four: $\alpha = 0.05/4 = 0.0125$ (Mundfrom, Piccone, Perrett, Schaffer, & Roozeboom, 2006). The effect size of the listening intervention was estimated using comparable literature. For example, there is evidence that spiritual interventions had a “significant moderate effect” in two separate meta-syntheses of the literature (Oh & Kim, 2014; Pantuso, 2015). “Moderate” equates to a value of 0.5 using Cohen’s d (Lund and Lund, 2021). However, to avoid overclaiming a more conservative estimate was used: Cohen’s $d = 0.4$.

So, conducting a paired sample t-test with effect size (Cohen’s d) 0.4, power 80% (also by convention) and $\alpha = 0.0125$ (by convention and adjusted by Bonferroni correction), G*Power version 2 calculated a minimum sample size of 62.

Results

Records of attendance at CCL were not standardized across the country, so it is difficult to state how many people attended CCL during the study period and did not take part. Further, there was no record of how many patients were asked to take part in the study but declined. For reference, the largest CCL resource in Scotland recorded 2000 visits in 2019, which was part of the study period, so the final number recruited are likely to be less than 10% total population.

The study recruited 143 participants in total, 100 females and 43 males, with age ranging from 17 to 87, mean (sd) 47.5 (16) years. Nineteen participants described themselves as religious, 28 spiritual, 22 both religious and spiritual and 72 neither spiritual or religious. Mean (sd) PROM scores at entry to the study was 7.79 (3.5) and at follow up 12.11 (3.4). EQ-5D-3L scores at the same points were $-1(.35)$ to $-2(.35)$ respectively, with visual analogue scale (VAS) equivalents: 55 (20) to 68 (18.5) (Table 3). Most people were seen by chaplains two to three times, and discharged themselves between four to six weeks after first visit.

Hypothesis testing

1. Patients will record higher scores on the Scottish PROM after CCL.

No outliers were detected, and assumptions of normality were not violated, as assessed by Shapiro-Wilk’s test ($p = 0.116$). A paired-samples t-test was therefore used to determine whether there was a statistically significant mean difference between PROM scores pre and post intervention. Participants scored higher on the PROM after intervention (12 ± 3.5) as opposed to baseline (7.94 ± 3.4), a statistically significant increase of 4.06 (95% CI, 3–5.12), $t(50) = 7.7$, $p < 0.0001$, $d = 1.08$, a very large effect size. Patients recorded significantly higher scores on the Scottish PROM after CCL intervention.

2. Patients will record higher scores on EQ-5D after CCL.

There was no need to further investigate EQ-5D-3L scores as they were lower post intervention than at baseline (Table 3). The visual analogue scale showed improvement

Table 3. Demographics, baseline and post intervention (after) measures.

Measure	N	Minimum	Maximum	Mean	Std. Deviation
Age	143	17 yrs	87 yrs	47.5 yrs	16 yrs
Religious	19				
Spiritual	28				
Both	22				
Neither	72				
Male	43				
Female	100				
PROM baseline	137	1	19	7.79	3.466
PROM after	55	5	18	12.11	3.435
Experience	53	9	16	15.77	1.17
VAS baseline	134	10	95	54.69	20.161
VAS after	54	14	95	67.61	18.488
EQ-5D-3L baseline	134	-.594	.850	-.09810	.350850
EQ-5D-3L after	56	-.594	.746	-.20429	.347121

N: Number of responses; VAS: Visual Analogue Scale.

though, so assumptions on the data were checked so the most appropriate test could be used to test whether there was a statistically significant mean difference between VAS scores pre- and post-intervention. No outliers were detected but the assumption of normality was violated for post intervention VAS, as assessed by Shapiro-Wilk's test ($p = 0.019$). Because normality was violated, the non-parametric Wilcoxon Signed Rank test was run and showed a significant difference between paired ranks ($p = 0.0001$), showing post intervention VAS scores were significantly higher than they were at baseline.

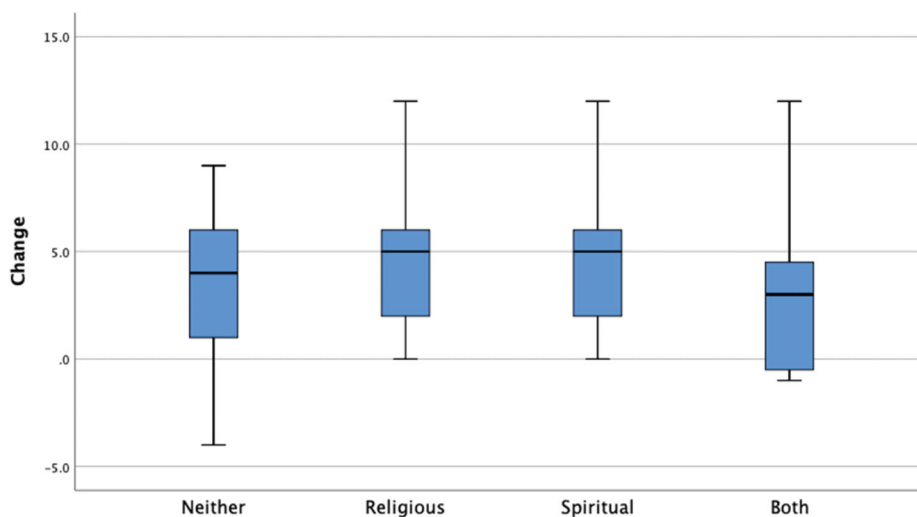
A paired t-test was also run to cross check the result because the t-test is robust to deviations from normality (M. Lund & Lund, 2017). It confirmed participants scored higher on the VAS after intervention (68 ± 318) as opposed to baseline (56 ± 19.5), a statistically significant increase of 12 (95% CI, 5.4–7.5), $t(52) = 5.37$, $p < 0.0001$, with large effect size (Cohen's $d = 0.75$) (M. Lund & Lund, 2021). In summary, the visual analogue scale results showed a significant improvement post intervention, whereas the Likert scale elements did not. This was a mixed result.

3. *The patient experience of CCL will be associated with Scottish PROM scores.*

Patient experience was measured by responses to the four questions described above, on a five-point Likert scale. These responses were almost universally as high as they could possibly be, with an average score of 15.7 out of a possible maximum score of 16. In other words, patients ticked "all the time" to all four items in the survey in Table 2, nearly every time. Whilst excellent as feedback to the participating chaplains, unfortunately this ceiling effect and subsequent lack of variance in the results rendered further analysis impossible. The patient experience of CCL was not associated with Scottish PROM scores in this study.

4. *There will be no difference in outcome according to whether patients self-describe as religious, spiritual, both, or neither.*

Following assumption testing a one-way ANOVA was conducted to determine if the change in PROM scores was different for different faith/belief groups. Participants who completed both baseline and post intervention questionnaires self-classified as religious



Mean improvement in			
Religion	PROM	Sd	N
Both	3.1	4.2	8
Neither	3.6	3.8	22
Religious	4.7	3.3	10
Spiritual	5.2	3.9	10

Figure 1. Boxplot and table of mean (sd) values of the change in PROM scores according to faith/belief group. Note all mean changes were positive.

($n = 10$), spiritual ($n = 10$), both ($n = 8$) or neither ($n = 22$). PROM scores for these groups increased in all groups, from “both religious and spiritual” (3.1 ± 4.2), to neither (3.6 ± 3.8), to religious (4.7 ± 3.3) to spiritual (5.2 ± 3.9), in that order, but the differences between these groups were not statistically significant, $F(3, 46) = .65$, $p = .587$. See boxplot in Figure 1. There was no difference found in outcome according to whether patients self-described as religious, spiritual, both, or neither. Chaplains were associated with improvement in PROM scores, regardless of participant’s faith or belief.

Discussion

Community Chaplaincy Listening was associated with a statistically significant positive impact on patients. Patients scored on average 8 out of 20 on the Scottish PROM before seeing the chaplain. Following intervention, they recorded average scores of more than 12. To put this in context, a PROM score of 8 would have situated them in the bottom 6% of a large ($N = 1116$) international sample of people who had also completed a Scottish PROM after seeing a chaplain (Snowden et al., 2021). The CCL post intervention average score of 12 was the same as this international post chaplain population’s average. In other words, participants in CCL recovered from scores nearly two standard deviations below the mean before the intervention, to scores consistent with those

scored by a comparable international sample of people who also no longer needed to see a chaplain. CCL patients discharged themselves from chaplain care when they were no longer in spiritual distress.

This is important because it demonstrates that chaplain interventions are associated with a clinically meaningful improvement. The key psychometric concept underpinning this conclusion is the “minimally important clinical difference” (MICD) (Skolarus et al., 2015). The MICD is the smallest change in any self-report scale that translates into a personally noticeable improvement in whatever the scale is measuring. This concept applies to all self-report measures (as long as they are valid), and unfortunately there is no consensus on the best way of calculating MICD because of the variability in these measures. There are conventions though. For example, half a standard deviation is used as a “rule of thumb” by many (Coretti, Ruggeri, & McNamee, 2014; McGlothlin & Lewis, 2014). Some use the standard error (Copay, Subach, Glassman, Polly, & Schuler, 2007), and others use bespoke methods. A critique of these different methods is beyond the scope of this paper (see e.g., Cook, (2008)), but the salient point is that the improvement in PROM scores recorded here far exceeded *all* of the different recommended metrics suggested in the literature. In this study, CCL was associated with a clinically meaningful difference to the patients they saw. They provided spiritually meaningful interventions to people who needed them.

The EQ-5D-3L results were more difficult to interpret. They were hypothesised to improve from baseline, but not in the same way as scores on the PROM, because if they had, there would have been no need for both measures. However, the EQ-5D-3L values not only deviated substantially from those seen with the PROM but were further notable for starting and remaining extremely low. EQ-5D-3L measures “health related quality of life” and has been used in thousands of studies internationally to calculate cost and benefit of different interventions. It is so widely used that each country uses a different formula to adjust the scores according to local cultural interpretations of health-related quality of life. The best possible score in every country is one, equating to full health. The worst possible score was originally designed to be zero (death), but in each country it varies considerably.

Table 4 shows that in Japan this “worst possible state” in every item generates a total EQ-5D-3L score of -0.111 , equating to a health state slightly *worse* than death. The same set of responses equates to a similar score of -0.109 in USA but translates to -0.329 in Netherlands and -0.570 in the UK, meaning people in these countries rate this health state as being even worse. More importantly, the EQ-5D-3L scores recorded both before and after intervention here are on a par with the very lowest recorded in the literature for *any* health condition. In a systematic review of 207 international studies using EQ-5D-3L, only diseases of the nervous system were equated with a mean EQ-5D-3L range including a negative figure (-0.2 to 0.15) (Van Wilder et al., 2019). Some other EQ-5D-3L ranges are illustrated in Table 5.

So, given any negative score means “worse than dead” using EQ-5D-3L, our cohort self-reported their health-related quality of life to be slightly worse than dead at baseline and still worse than dead on follow up. It is difficult to square this with their scores on the PROM and especially with their scores on the associated visual analogue scale (VAS), where their scores improved significantly the following intervention. Perhaps the most important

Table 4. How UK, USA, Japan and Netherlands interpret Health Related Quality of Life as measured by EQ5D-3L in three example states: 1. No problem, 2. Moderate problem, or 3. Worst Possible problem in all five items of EQ-5D-3L.

		EQ-5D-3L items:					EQ-5D-3L totals in different countries				
		Mobility	Self care	Usual activities	Pain/Discomfort	Anxiety/Depression	UK	USA	Japan	Netherlands	
Level 3	Worst possible	Worst possible	Worst possible	Worst possible	Worst possible	Worst possible	-.57	-.109	-.111	-.329	
Level 2	Moderate	Moderate	Moderate	Moderate	Moderate	Moderate	.516	.597	.532	.569	
Level 1	No problem	No problem	No problem	No problem	No problem	No problem	1	1	1	1	

Note the worst possible scores show greatest variation. A score of less than zero is "worse than death."

Table 5. Selection of mean EQ-5D ranges in a selection of chronic diseases as reviewed by Van Wilder et al. (2019).

Chronic disease chapter (ICD-10)	Number of studies included in review	Mean EQ-5D range
Neoplasms	38	0.45–1.00
Endocrine, nutritional, and metabolic diseases	57	0.31–1.00
Mental and behavioural disorders	46	0.11–0.97
Diseases of the nervous system	41	–0.20–0.92
Diseases of the circulatory system	50	0.30–0.97
Diseases of the respiratory system	36	0.47–0.95
Diseases of the digestive system	17	0.49–0.92

Note only diseases of the nervous system entailed a negative value, as did mean scores in this study.

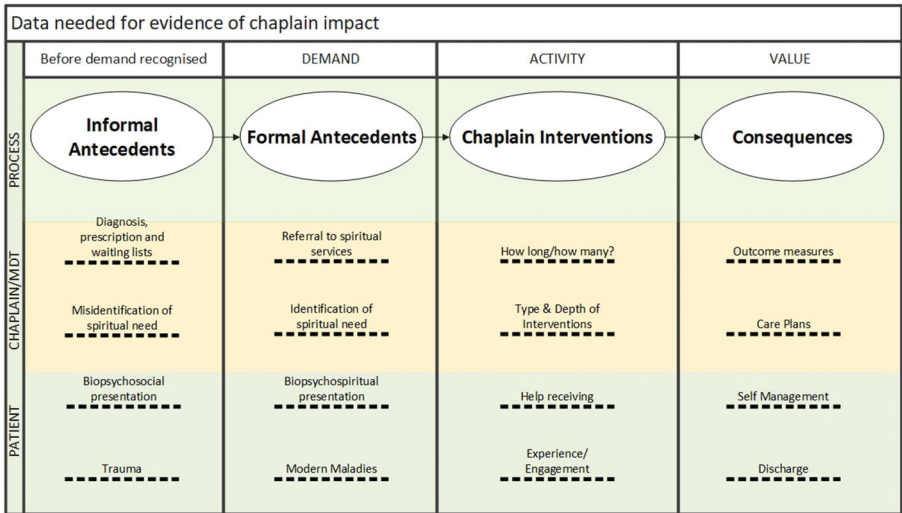


Figure 2. How evidence helps to improve the process of healthcare chaplaincy in primary care.

conclusion from a practice perspective is that the people referred to chaplains in this study were the people most in need of support. People scoring equivalently are often excluded from services because they are so “difficult to treat” (Snowden, Young, & Savinc, 2020). The chaplains in this study were seeing exactly who they should have been seeing.

The third hypothesis couldn’t be tested. Almost every participant gave their chaplain the maximum possible score on every item for their feedback on experience of the encounter (see Table 3). Whilst this is encouraging feedback for the chaplains, it is less helpful in identifying different elements of chaplain encounters that patients may value more than others. Without exception every patient felt listened to, able to talk about what was on their mind, had their faith/beliefs valued, and were understood.

Finally, and consistent with Liebroer and Nagel (2021), there was no significant difference found in outcome according to whether patients self-described as religious, spiritual, both, or neither (Figure 1). Everyone benefitted from the intervention. Some authors have suggested that chaplains appear to offer greater benefit to those who are already religious or spiritual (van Dijk, 2021), and there is evidence that religious people score higher on *baseline* measures of the Scottish PROM than non-religious people (Snowden, Vandenhoeck, & Verhoef, 2020), meaning non-believers may gain greater relative benefit from seeing a chaplain for their spiritual issues. Nevertheless, there was

no difference found here and so the chaplains in this study helped all of those in need, regardless of faith.

Limitations

The study failed to identify elements of the experience of chaplain interventions of value to individuals. This is a problem for the reasons introduced earlier. It is difficult to separate out what benefit a chaplain listener offers over and above a counsellor, psychologist or volunteer, for example. It is difficult to see how questions of comparison can be answered without relevant trials, and this will need substantial funding as discussed.

Another unexpected issue was the lack of improvement in the EQ5D-3L scores. It is difficult to understand how such a substantial improvement in PROM scores, paralleled by a significant improvement in global EQ5D measures, were *not* paralleled by any improvement in EQ-5D-3L scores. Fellow chaplain researchers have suggested that CCL works primarily by reducing anxiety (Gibbon & Baldie, 2019). However, even comparing just the EQ-5D-3L item on anxiety before and after intervention didn't show any change. This is even more confusing given the anxiety item on the PROM *did* show significant improvement when considered stand alone, in line with previous investigations in CCL (Gibbon and Baldie, 2019), and studies internationally (Blum, Rutt, Nash, Joyce, & Buonopane, 2021; Simeone, Berning, Hua, Happ, & Baldwin, 2021), where reducing anxiety was also seen as an outcome of chaplain interventions.

Perhaps EQ5D-3L was too "blunt" in which case other quality of life measures such as WHOQOL or WHOQOL-SRPB might have been better for identifying spiritually relevant change in quality of life (Krägeloh, Billington, Henning, & Chai, 2015; World Health Organization, 2012). Other "wellbeing" metrics such as the Warwick and Edinburgh Mental Wellbeing Scale (WEMWEBS) (Stewart-Brown, 2015) have successfully been used previously too, both in validating the Scottish PROM in early studies (Snowden & Telfer, 2012; Snowden, Telfer, Kelly, Bunniss, & Mowat, 2013b) and also in measuring the impact of chaplains in primary care too (Kevern & Hill, 2015; G. W. Macdonald, 2018). One or more of these measures could be added in future studies.

There are three key elements of any intervention to study: 1, what happened before (the "demand" phase), 2, what happened during (the intervention, or "activity" phase), and what happened after (the "value" or consequences of the intervention). However, there are many attributes to these three components (Figure 2), and so in any study a balance always needs to be struck between obtaining the best data to improve the process without burdening patients by demanding too much data.

In relation to recruiting participants more generally, a similar balance with gatekeepers holds. Ideally every person who met the inclusion criteria should have been invited to participate, but this rarely happens in practice for a range of reasons, from clinicians forgetting about the study through to active disengagement with it (Snowden & Young, 2017). Further, despite recruiting well beyond target with 142 participants at baseline, less than the aimed for 62 completed *all* before and after measures in every case. However, every follow up measure had at minimum 53 participants and as mentioned earlier the t-test family of statistical tests is robust in less than ideal circumstances

(Lund & Lund, 2017), with the paired t-test particularly so. For example, one of the major sources of variability is usually found *between* subjects, but in this study each subject acted as their own control, so this variability was never a factor (Swinscow, 1994). It is likely the results are valid.

More problematically, there was incomplete data on the length of time people were in the study for, and on how many times participants saw the chaplain. This is essential information for commissioners, along with data on the longer-term impact of the service. For example, did anyone “remit” and go back to GP? Anecdotally they didn’t, but rather returned to CCL if needed. Nevertheless, the CCL service will need to establish a national method of collating these data. Previous studies have shown that chaplaincy interventions follow a type of “dose dependent curve”: the first meeting with a chaplain has the largest impact, and the second adds a little more. The third meeting adds proportionally less again, and there is no further gain after four meetings (Snowden & Telfer, 2020). From the data that was collated, chaplains reported that two or three sessions appeared to be the norm in this study and that participants self-discharged after a month. Finally, for this limitations section, there are the usual caveats about generalizability and transferability. This was a small sample study in a single country.

Conclusion

Community Chaplaincy Listening worked in primary care. This is consistent with previous studies of chaplains working in primary care in UK (Gibbon & Baldie, 2019; Giffen & Macdonald, 2020; Kevern & Hill, 2015; Macdonald, 2018; McSherry et al., 2016). Chaplains’ ability to support people presenting with complex bio-psycho-social issues had two major benefits. First and foremost was the individual benefit. People felt better after CCL. Chaplains listened to people who were in spiritual distress and the outcome of this intervention was that these people felt less anxious, more in control, had a better outlook on life, and a greater sense of honesty and peace. Second was the wider impact of this personal spiritual improvement on multidisciplinary colleagues. Chaplains helped to support people who have historically been very difficult to help. It is possible that these “hard to help” people have been hard to help because some of their problems were never “bio-psycho-social” in the first place, but spiritual. Better targeted use of the chaplain in multidisciplinary teams therefore not only helps patients, but it also has potential to positively affect the morale of health and social care colleagues, who have historically not been able to help some of these people and found themselves burned out as a result.

The findings from this study therefore show how healthcare chaplains can work in primary care. All health and social care specialists are of greatest value when they are using their specialist skills to help those with the greatest need. Identifying those in the greatest need is therefore central for healthcare chaplaincy, and this study has shown that not just the Scottish PROM but the EQ5D could do this in primary care. International replication studies are needed, because if transferable, then two short, free to use measures could not just help to identify people who may benefit from healthcare chaplaincy, but also focus healthcare chaplaincy on those with the greatest need.

Note

1. <https://learn.nes.nhs.scot/47620/person-centred-care-zone/spiritual-care-and-healthcare-chaplaincy/community-chaplaincy-listening-ccl/community-chaplaincy-listening-ccl-training-manual>

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